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ABSTRACT

This manual is intended to assist New York State agencies in the "Community Integration Project in Aging and Developmental Disabilities." The first section chronicles experiences of various agencies in carrying out long-term planning, training, and program development for this population. The second section explains federal developmental disabilities statutes, common aging terms, effects of aging on specific disabilities, and incidence estimates. Other sections discuss federal acts that directly affect older persons with developmental disabilities; potential barriers to integration; strategies for overcoming these barriers (including policy, attitudinal, information, communication, and financial barriers); guidance on state and area plan requirements including gathering information and plan development; activities that can be undertaken by state developmental disabilities planning councils, state units on aging, and state developmental disabilities agencies to bridge systems and build partnerships; how to provide for short-term and long-term training needs including inservice activities and course infusion at the university level; and program options for this population including day programs, retirement, family supports, housing options, and adaptations of physical environments. Of special interest to educators is chapter 8 entitled: Developing Training and Education Programs". Appendices include data from demonstration projects, population tables, sample agreements, a list of national associations, and a list of 36 bibliographic resources. (DB)

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Planning and Community Development in Aging and Developmental Disabilities

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Other CIPADD Publications

The Wit to Win: How to Integrate Older Persons
with Developmental Disabilities
into Community Aging Programs

Serving Seniors with Severe Disabilities

Casebook of Integration Experiences

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Building the Future

Planning and Community Development in Aging and Developmental Disabilities

Matthew P. Janicki, Ph.D.
Project Director

1991

New York State Office of Mental Retardation and Developmental Disabilities
Mario M. Cuomo, Governor
Elin M. Howe, Commissioner

Community Integration Project in Aging and Developmental Disabilities

A joint project of the New York State Developmental Disabilities Planning Council, the New York State Office of Mental Retardation and Developmental Disabilities, the New York State Office for the Aging, the University Affiliated Program for Developmental Disabilities of the University of Rochester School of Medicine and Dentistry, the Institute of Gerontology at Utica College, the Brookdale Center on Aging of Hunter College, and the Rome Developmental Disabilities Services Office.

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Community Integration Project in Aging and Developmental Disabilities

In October 1990, the federal Department of Health and Human Services, Administrations on Aging and Developmental Disabilities, funded the "Community Integration Project in Aging and Developmental Disabilities" (CIPADD) to develop national technical materials that would promote and assist in the community integration of seniors with developmental disabilities. The work of the CIPADD is carried out through the cooperative efforts of several New York state agencies and aging-based university programs and has the following specific goals:

- *expand upon developed technical "how-to" manuals detailing successful strategies for coordinating programs and services for older persons with developmental disabilities and older parents of adults with developmental disabilities, and*
- *provide technical assistance in implementing methods addressed in the manuals and materials.*

The project's objectives are to:

- *develop materials that identify barriers to collaboration and methods used to overcome barriers to access to community aging network services;*
- *develop materials that aid in developing linkages with relevant agencies that share concerns in the area of aging and developmental disabilities;*
- *develop materials that illustrate various models of integration of older persons with developmental disabilities into aging network programs;*
- *disseminate nationally information and materials that assist in the integration of older persons with developmental disabilities into aging network programs; and*
- *provide technical assistance to enhance self-help capabilities among state, regional, and county aging and developmental disabilities networks.*

This manual is one of the materials produced under this project, others are listed on the inside of the front cover.

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About this Manual

Each section addresses specific issues and offers suggestions for activities. Information is presented in roman type and suggestions for activities are presented in *italics*. Suggestions are presented to represent a variety of conditions; some may or may not apply to your specific situation. Footnotes are placed within the sections offering supplemental information or references. References are repeated in the Appendix. Tables and additional reference matter are in the Appendix.

1 Chronicles the experiences of various New York agencies in carrying out a longterm planning, training and program development effort designed to aid the integration of older persons with developmental disabilities into community senior programs.

2 Explains federal developmental disabilities statutes, common aging terms, and how specific disabilities are affected by aging, and offers suggestions for estimating the number of older persons with developmental disabilities.

3 Reviews federal acts that directly affect older persons with developmental disabilities.

4 Identifies a range of potential barriers to integration and provides tips on identifying the presence of such barriers in your area.

5 Offers some possible strategies for overcoming barriers to integration that may be exist in your area.

6 Provides help with state and area plan requirements and offers suggestions for gathering information and developing plans on aging and developmental disabilities.

7 Identifies activities that can be undertaken by state developmental disabilities planning councils, state units on aging, state developmental disabilities agencies, and others to bridge systems and build partnerships.

8 Explains how to provide for shortterm and longterm training needs, through developing training and education resources, providing crosstraining and inservice activities, conferences and workshops, and by course infusion at the college or university level.

9 Explores a number of program options for older persons with developmental disabilities and suggestions for program development activities.

This manual is printed in Palatino 11pt type.

Foreword

Here is an overview of what New York has experienced and of lessons learned in "building the future" for seniors with lifelong disabilities -- as we seek to create a range of services for seniors with developmental disabilities in the mainstream of the aging network. Here also is information on issues related to aging and developmental disabilities as well as those which affect planning and community development.

This how-to manual assumes that both generic and specialized systems of care and services are needed to plan for accommodating older persons with lifelong disabilities. The aging network and the disabilities system must not only communicate, they must integrate their activities to make the most of the functional ability of the older person being served.

To help you identify local barriers to planning, networking, training and program development, an overview of a range of barriers that may be encountered is offered, along with possible strategies to overcome them. The manual contains specific sections on aids to planning, networking, training and program development and a brief overview of key federal enabling legislation to help you in your efforts.

Building the Future was developed to aid localities and states in meeting the needs of older and elderly persons with lifelong disabilities. While it reflects the experiences of a particular team of workers, it has universal applications that span cultural, geographic, sectional, political, and philosophical differences. We hope you will find this publication useful as you work to improve the older age situations of the nation's senior citizens with developmental disabilities.

CIPADD Team Members
Albany, New York City, Rochester and Utica-Rome, New York

Preface

The *New York Times,* in an editorial, pointed out that an increasing number of older Americans want to live out their lives in their own homes and in their own communities.[1] It noted the growth of naturally occurring retirement communities -- or NORCs, such as buildings and neighborhoods in which many older adults remain or tend to gravitate toward. The point of the editorial was that public policy has done little to attend to the evolving needs of an increasingly greater proportion of America's population -- those older Americans living at home. Older people, regardless of their background, feel comfortable in surroundings in which they feel an affinity and which contain things that are familiar. The editorial aptly noted that what gerontologists call "aging in place" is a phenomenon that may contribute to prolonged independence and an enhanced quality of life. However, it went on to conclude that Congress and the various levels of government have done little to make the connections between supportive housing, social services and health care policies for older adults who wish to remain at home.

A number of years ago, our colleague Dr. Paul Cotten listed what he termed the basic rights of older persons with developmental disabilities.[2]

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[1] "The Best Home for Older Adults," Editorial in the *New York Times*, August 17, 1991, p. 20.

[2] These are reproduced in the companion manual, *The Wit to Win: How to Integrate Older Persons with Developmental Disabilities into Community Aging Programs.* They originally appeared in S.S. Brody & G.E. Ruff (eds.), *Rehabilitation and Aging: Advances in the State of*

These enumerated rights were no different from those we would ascribe to ourselves, our parents, relatives, or friends. However, the critical object lesson from this listing was that the rights had to be articulated at all. Our society, generally, and the collective fields of developmental disabilities and aging more specifically, had not yet, to their discredit, recognized that persons with mental retardation and other developmental disabilities grew into old age, that their presence in community settings was to become a more pronounced natural occurrence, and that they were entitled to grow old with the same dignity as other people.

Over the past number of years, there has been significant advocacy for equal treatment and acceptance within society of Americans with lifelong disabilities. This advocacy has paid generous dividends. We now have explicit federal legislation that mandates equal access in public settings, special assistance to make independence a more realistic goal, and targeted efforts to enable community integration to occur. Indeed, with regard to advocacy and community integration, different schools of thought have evolved as to how to attain the fullest integration for older persons with developmental disabilities within natural communities. Some have argued that involving older persons with developmental disabilities with other older persons is demeaning and counter to sound integration principles, because it lumps together two groups that can be perceived as devalued. Others have posited that the choices offered to older persons with developmental disabilities must include the opportunities for inclusion in senior programs and activities and that involvement with age peers is a beneficial, normal occurrence.

We would offer that no matter what strategy one feels most comfort with, knowledge of the aging network and its options is an important element in any effort to effect assimilation and integration. Knowledge of the fundamentals of community development, knowledge of the intricacies of the systems of services or amenities available to older Americans, and knowledge of the issues facing this particular age group are all crucial to sound efforts at promoting and effecting inclusion and enhancing quality of life in old age.

The editorial in the *New York Times* is an object lesson that society is still wrestling with the very same issues that we in the field of developmental disabilities and aging have already faced. Confronted with a dramatic growth in the numbers of older Americans with developmental disabilities, we have recognized that for these individuals, in many cases, simple supports to an existing situation may mean the difference between continuing to reside at home or having to be institutionalized. With society coming to the realization with what the "senior boom" will mean, it is timely for us to begin to show what can be done by cooperative efforts, strategic placement of supports, and improving existing senior services. Critics may say that the nation's present senior services are poorly underwritten and slow to respond to the demands within their communities. We argue that while such examples exist, the bulk are well

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the Art (see P.D. Cotten & C.L. Spirrison, *The elderly mentally retarded [developmental disabilities] population: A challenge for the service delivery system*, pp. 159-187), New York: Springer, 1985.

run, user-friendly, and are more democratic than many of the specialized services that historically have been available to persons with developmental disabilities.

Our focus in this manual is simple. We believe that people should have choices and that those choices are based upon options. We believe that older persons with developmental disabilities should have access to the programs that treat their users as valued human beings and which promote normal usage, not stereotypic deviance. We believe that although the aging process has an eventual outcome that is common to all, older persons – while aging – still have great potential and should have the independence and autonomy to make their own decisions about what their life course will be and how they wish to spend their remaining years. We believe that older individuals with developmental disabilities are persons whose capabilities demonstrate great variability; some have pronounced difficulty due to their disabilities, others do not. But, mostly we believe that the labelling of a person as one with a developmental disability bears no purpose in old age and that the functional capabilities of the individual are the most important determinants of what a person can or can not do.

We've designed this manual so that you, the reader, can extract what you need to make your efforts that much more productive. We have not set any particular agenda for what should be done. That is up to you and the older persons with whom you work or represent. Our intent is to provide you with the information to make your efforts more facile and productive. Certainly, we would be remiss if we didn't admit that we have a particular goal as an end to our efforts – consistent with that of the editorial in the *New York Times* – that public policy adequately address the needs of all older Americans and make "aging in place" a means of living one's life as fully and independently as possible, with the all supports one needs to maintain oneself in one's home. And by all, we mean building a future that includes all older persons with developmental disabilities within what will have to become a broader and more encompassing system of senior services.

Section 1

Lessons Learned: The New York State Experience

The New York State experience in planning and community development for older persons with developmental disabilities covers a number of special initiatives undertaken over a ten-year period. It involved cooperation and supportive working agreements with the New York State Developmental Disabilities Planning Council (DDPC), the New York State Office of Mental Retardation and Developmental Disabilities (OMRDD), and the New York State Office for Aging (SOFA). It also involved initiatives undertaken by local groups and university programs.

What follows is a chronology of events and activities along with an outline of the lessons we learned. We hope you find our experiences helpful for your planning and community development efforts.

Assessing needs

In the early 1980s the DDPC, OMRDD and SOFA began to focus attention on the State's growing population of older adults with developmental disabilities.[1] This came about because:

- many of the State's providers realized that they had increasing numbers of seniors still working in sheltered workshops or growing older in their residences;

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[1] In New York State, there are 62 counties (57 upstate as well as New York City's five boroughs) and 59 area agencies on aging (AAAs). The state's 1990 older population represents 17% of the total state population of some 18 million; it is estimated that there are about 16,000 older New Yorkers with a developmental disability.

- a number of state developmental centers had increasingly larger older populations which would exceed half of the general center population within ten years;
- clinicians were requesting information on how to best meet the needs of seniors with developmental disabilities; and
- the pending closure of some of the State's developmental centers was creating a need for more community-based programs.

Beginning in 1982, a series of presentations about the aging of the population of older adults with developmental disabilities were given across the state. Also in 1982, the OMRDD applied for a planning grant to the federal Administration on Aging to support an investigation of the character and needs of the older population of persons with developmental disabilities within New York State. Although the grant application was approved, it was not funded. The project, however, was carried out on a reduced scale with State funds and provided valuable information that was included in a 1983 state report on aging and developmental disabilities..

In 1983, two state agencies (OMRDD, SOFA) and the state developmental disabilities council (DDPC) cooperated to produce the *Report of the Commissioner's Committee on Aging and Developmental Disabilities.*[2] The *Report* provided information on the demographics of the state's population of older adults with developmental disabilities, the various agencies providing services to elderly persons, and the problems faced by older persons with developmental disabilities. It also included a series of recommendations.

One recommendation was to conduct a statewide conference to disseminate information and stimulate networking and program development in aging and developmental disabilities. In February, 1985, the three agencies jointly sponsored a statewide conference in Syracuse, New York that drew some 600 participants. Another recommendation was the modification of a regulation that required a set number of daily hours of programming, irrespective of age. This regulation was changed by eliminating the specific hours requirement, while keeping intact the spirit of the programming standard.

Another recommendation was to find out what programs and services were available and needed. The OMRDD conducted a national study of state developmental disabilities and aging agency plans to determine what initiatives were being carried out and to what extent planning was being done to address the needs of older persons with developmental disabilities.

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[2] A detailed description of the development and workings of this select committee are contained in the document. The Commissioner of OMRDD appointed some 60 individuals, representing diverse sectors of the state, to sit on one of three subcommittees: planning, program, and health. These individual subcommittees met and produced the relevant sections of the draft report. These sections were then synthesized into a final report containing recommendations and action steps.

This study established a baseline for State activities and helped us to understand where New York State stood in relation to other states[3].

Another of the *Report's* recommendation was to develop an inventory of existing programs that served older persons with developmental disabilities. OMRDD carried out a survey of the State's providers and 35 residential, day and support programs serving seniors with developmental disabilities were identified. An additional recommendation was to set up day and residential retirement-oriented programs, as well as to explore using existing aging network programs. Although the provider survey showed that there were some specialty programs, no integrated community programs were operating. It was clear that a series of demonstration projects testing the feasibility of integrating older persons with developmental disabilities into aging network programs should be tried.

> ***LESSONS LEARNED...***
>
> *We learned that the first step is to assess the population, determine its needs, and disseminate information. Use a plan or report to define who you are addressing, who does what, what needs to be done, and how it can be done. It helps to put boundaries around the issue for planning, budgeting, and development actions. Such a plan or report will also build acceptance of the problem and consensus on how to approach it.*

To aid the expanding efforts, OMRDD began a partnership with the State Office of the Aging.[4] In 1986, SOFA staff, with funding from the DDPC, and with support from the OMRDD, developed a project that tested the feasibility of various models of integrating older persons with developmental disabilities in aging network programs such as senior centers, nutrition sites, and adult day care. The activities of the *Aging & Developmental Disabilities Integration Project* (as it came to be known) were conducted in three phases:

- Phase I - Analyzing barriers and developing strategies for integration.
- Phase II - Selecting and implementing demonstrations to test

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[3] The results of the study were first distributed as an internal report and then published in the journal *Mental Retardation* (See Janicki, M.P., Ackerman, L. & Jacobson, J.W. State developmental disabilities/aging plans and planning for an older developmentally disabled population. *Mental Retardation*, 1986, 23, 297-301).

[4] As part of this arrangement, SOFA assigned a succession of staff people to the developmental disabilities project. These positions were funded through a series of special grants from the Council. These staff included I-Hsin Wu, who was the author of the original "Barriers and Strategies Report" and then transferred to another assignment; Stocky Clark, who managed the start-up effort and recruited I-Hsin Wu and who has since gone on to the New York State Division of Housing and Community Renewal; and Philip LePore, who developed the "Wit the Win" manual and continued as his agency's liaison to the project. In addition, Robert O'Connell, Deputy Director at SOFA, encouraged and oversaw the efforts of the SOFA-OMRDD collective projects since their inception in 1983.

integration strategies.

- Phase III - Evaluating demonstrations and developing a how-to manual to guide service providers in establishing integration programs.

Phase I activities resulted in the report, *Barriers to and Strategies for the Integration of Older Persons with Developmental Disabilities within Aging Network Services*. The report is a compendium of information on what was and what was not working to aid integration within the State.[5] One finding was that aging network programs could assimilate those older persons who were independent or functionally able and provide needed services. For others, the OMRDD could develop retirement-oriented or other kinds of specialty programs. Now the State was ready to carry out its first series of program demonstrations.

The first series of demonstrations

During Phase II agencies in four upstate counties were asked to test the feasibility of integrating older persons with developmental disabilities into community senior programs. The demonstration projects which were supported by the DDPC were placed in two rural and two urban counties.[6] They used congregate meal sites, adult day care sites, and senior centers. The demonstrations also relied upon a variety of staffing patterns including volunteer companions, paid companions, paid staff and shared staff to assist in the integration process.

The demonstrations involved community education activities, outreach and casefinding, shared staffing arrangements in senior centers, cross-training, cross referrals between aging and mental retardation agencies, and other sharing arrangements in areas such as transportation, community living, and family supports (see Table 1a in Appendix A). In each instance, the projects were successful in demonstrating that the integration of elderly persons with developmental disabilities into generic senior settings can be done. The four demonstration projects had a collective goal to integrate a total of 55 seniors; during the first year the goal was exceeded and 70 seniors with developmental disabilities were successfully integrated into 17 local aging service sites.

The most significant finding from these demonstrations was that integration of older persons with developmental disabilities into generic aging service programs was not only feasible, but that it could be highly successful when special efforts were made to make integration occur. What else did these demonstrations tell us?

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[5] A revised version of the report's "barriers and strategies" comprises Sections 4 and 5 of this Manual.

[6] For example, we asked (1) a rural area agency on aging (AAA) to integrate older individuals with developmental disabilities into nutrition sites and senior centers; (2) a rural AAA to provide adult day care and targeted outreach for older adults with developmental disabilities; (3) an urban mental retardation agency to develop staff sharing arrangements with the city's senior centers to facilitate their use by older adults with developmental disabilities; and (4) an urban aging agency to serve as a broker or "matchmaker" between the services that older individuals with developmental disabilities need and the available aging network programs.

- a key individual is crucial in brokering or advocating for change in agency practices or policies to advance the interests of older individuals with disabilities;
- although originally there were instances of reluctance to cooperate, agencies come to realize that working together, rather than competing, can benefit both service networks with cost savings and program options; and
- the infusion of funds, staff or other supports can stimulate integration activities and is an effective way to bring about change (support and technical assistance from state or other governmental specialists can be especially helpful).

With success of the demonstrations, the OMRDD and SOFA undertook a network-building and education effort which included conducting regional integration workshops and conferences involving local aging network providers and administrators, disability agency staff, and government officials. The presentations at these workshops were centered around lessons learned from the demonstrations, changes in the Older Americans Act, and a discussion of the State's aging services program development. Concurrent with the education and training effort, the DDPC awarded a grant to implement a planning and community networking project in New York City that led to the creation of the New York City Task Force on Aging and Developmental Disabilities.[7]

Other concurrent activities

By 1986, the groundwork had been set at the national level to help leverage support for integration efforts and to lay the foundation for eventual changes in the Older Americans Act.[8] The changes helped further to open the aging network to older persons with developmental disabilities and, in New York, helped the on-going efforts to integrate community aging programs.

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[7] When the original applications were submitted, we noted that the projects submitted from New York City were not offered within an overall context. It was decided that rather than fund random projects within New York City, first a master plan was needed to identify the course of integration efforts in the City. Thus, a support grant was awarded to the Brookdale Center on Aging of Hunter College to help develop a coalition of agencies invested in this area and to develop a strategic plan that would guide Council sponsored demonstration projects in New York City. An aging network sponsor, the Hunter-Brookdale Center on Aging, was selected because it was felt that the initiative for this project had to come from an aging network group. A disability agency or group would have appeared self-serving and may not have elicited the cooperation and participation of aging network agencies and consumer groups.

[8] In 1986, Dr. Matthew P. Janicki spent the year in Washington as a Joseph P. Kennedy, Jr. Foundation Public Policy Fellow. While at the National Institute of Aging, he aided the Institute with the issuance of its program announcement on older adults with mental retardation. In addition, while with the U.S. Senate's Subcommittee on Disability Policy

The following year, the OMRDD established the nation's first policy level bureau of aging services within a state mental retardation and developmental disabilities agency. During this period, the State also saw the evolution of a number of locally-originated network groups, composed of staff from agencies involved in serving seniors and agencies serving older persons with developmental disabilities.[9]

The new bureau surveyed some 450 agencies in New York State to develop a updated services directory of both voluntary and state agencies (in New York State, the OMRDD is also a major provider of community programs). Agencies were asked to indicate whether they operated a specific program or service for older persons with mental retardation or other developmental disability and to provide information on the number served, costs, hours of operation, location, and components of their program.

LESSONS LEARNED...

Educating agencies to carry out integration efforts can be done by establishing demonstrations within the provider community. It helps if the demonstration sites are run by articulate and respected persons. Their experiences become part of the practice of other agencies as the "word is spread." Not all demonstrations need funds; however, "money talks" and it helps to seed such efforts either with monies or other resources. The results are quicker gains and greater receptivity and cooperation.

The resulting *1987 Program Resource Directory for Older Persons with Developmental Disabilities* provided for the first time a listing of specialized services and programs for New York's older citizens with mental retardation and developmental disabilities which could be used for information and referral purposes; and gave providers serving older persons an idea of the scope of the network they could tap for program development. The programs listed in the Directory represented specialty and integrated programs; in addition, programs for all-age adults which

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(then known as the Subcommittee on the Handicapped), he worked on legislation that later became the "disability provisions" of the 1987 reauthorization of the Older Americans Act and provisions in the Developmental Disabilities Act that reference aging and that in 1988 established the network of university affiliated program (UAP) aging and developmental disabilities training centers.

[9] A number of these groups were active prior to efforts by the State to expand them; for example, the Western New York Consortium on Aging and Developmental Disabilities, which under the leadership of Paul Synor, Karen Little, and Mary Petrakos Terranova has evolved into a dynamic regional group; the Central New York Network on Aging and Developmental Disabilities which began as the Oneida County Mental Retardation/Developmental Disabilities Task Force Committee under the leadership of Angela VanDerhoof, Kathie Bishop and Dr. Ron Lucchino; and the Hudson Valley-Catskill Network on Aging which began as the result of the organizational efforts of Dr. Alvah Canfield.

serve a significant number of elderly persons were included. Some 121 different programs, operated by 84 agencies, were listed. In all, 38 of the state's 62 counties were included.

A national video on community integration, titled *"Aging... A Shared Experience,"* was produced in 1988 with the help of the OMRDD.[10] The video drew upon testimonials from such national leaders as Dr. T. Franklin Williams (Director of the National Institute on Aging), Congressman Claude Pepper, and Ms. Eunice Kennedy Shriver and was developed to aid in the promotion of community integration and the building of social supports. It was widely disseminated. Copies and a companion discussion guide were sent gratis throughout the state and to all the state units on aging, developmental disabilities planning councils, and state mental retardation/developmental disabilities authorities.

A follow-up provider survey was conducted in 1988 with inquiries sent to over 700 agencies representing the state and voluntary sector. Over 146 senior-oriented programs were reported in 43 of the counties. The 1989 version of the directory was distributed throughout the State. Because of its size (some 300 pages), distribution and printing became costly. It had served its purpose in identifying staff and programs; consequently, no further editions were produced.

During this period, the DDPC also established a subcommittee on aging concerns as part of its new committee structure. This committee was composed of members of the OMRDD, the SOFA, the Office of the State Advocate for the Disabled, various provider agencies, research programs, and university aging centers.[11] Its charge was to address unmet needs and unresolved issues related to the State's population of older persons with developmental disabilities and to make recommendations to the DDPC for aging-related actions.

In 1989, the aging concerns subcommittee was charged to undertake an examination of the pension options available to older New Yorkers with developmental disabilities. The Committee's report, *On the Feasibility of*

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[10] The *Aging... A Shared Experience: Discussion Guide* to the video describes the video, its contents, sponsors, participants, and offers background information for its use. Primary production support for the video and guide was provided by the Joseph P. Kennedy, Jr. Foundation, and additional support was provided by the Council, SOFA, the University of Rochester UAPDD, the University of Akron, the University of Maryland, the Elvirita Lewis Foundation, and the American Association of Retired Persons (AARP). Copies can be obtained from NYS OMRDD, 44 Holland Avenue, Albany, NY 12229-0001.

[11] The subcommittee was composed of Dr. Matthew P. Janicki of OMRDD (Chair), Dr. Alvah Canfield of the Sullivan County ARC, Dr. Arthur Dalton of the Institute for Basic Research, Ms. Mary Petrakos Terranova of PEOPLE, Inc., Ms. Jenny Overeynder of the University of Rochester, Ms. Roxanne Offner of the State Advocate's Office, Dr. Jack Gorelick of NYC AHRC, Dr. Ronald Lucchino of Utica College, Mr. Philip LePore of SOFA, and Mr. Arthur Maginnis of the state developmental disabilities planning council (subsequently, the members also included Ms. Henrietta Messier and Dr. Charlotte Parkinson). The subcommittee functioned not only as a preliminary planning body, but as a mechanism for bringing together network groups, drawing in consumer concerns, and providing a vision on aging concerns to the Council's overall activities.

Different Pension Support Systems for New York State Residents with a Developmental Disability[12], was circulated throughout the nation and became a key resource on the emerging issue of pension supports for older persons with developmental disabilities.

Phase III of the *Aging & Developmental Disabilities Integration Project* saw the production of an "how-to" manual, *"The Wit to Win: How to Integrate Older Persons with Developmental Disabilities into Community Aging Programs."* Complimentary copies were sent throughout the state and to all the state developmental disabilities councils, state units on aging, and mental retardation/developmental disabilities agencies, the network of university affiliated program aging and developmental disabilities training centers, and other interested associations and groups.

At the conclusion of Phase III, the DDPC awarded a grant to the SOFA to carry out a program of training and technical assistance on community integration across the state. Under the training program, a number of "Wit to Win" workshops were conducted to provide hands-on training on how to integrate community aging network programs. In the Western part of the state the workshops were coordinated with the University of Rochester's Training Program in Aging and Developmental Disabilities (TPADD), since the TPADD was also providing training in the area of aging and developmental disabilities. In New York City, they were coordinated with the New York City Task Force on Aging and Developmental Disabilities and the Brookdale Center on Aging of Hunter College.

The second series of demonstrations

We realized early on that the needs of all older persons with developmental disabilities could not be solely met by targeted integration efforts. Also, the aging network could not absorb all the seniors with a developmental disability, nor could it adequately provide a program for seniors with special needs (e.g., those with severe and profound impediments or behavior problems, those with more health related needs, and those who needed more time to adjust to being with other people).

To address this broader need, in 1989, the OMRDD funded six senior day program demonstrations across the State, each with a different approach to providing a retirement type program.[13] The model was a variant of social adult day care. The programs were fully funded by State monies under an OMRDD program demonstration initiative and were set up unencumbered by existing program regulations. The participating agencies were informed that in the future they may be required to comply with the regulations for social model adult day care to be issued by the SOFA.[14] One of the programs was located in a rural area, two in small towns, one in a large city, and two in New York City (see Table 1b in Appendix A).

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[12] This report is available from the New York State Developmental Disabilities Planning Council, 155 Washington Avenue, Albany, NY 12210.

[13] This series of demonstrations resulted from a general call (RFP: request for proposals) for innovative day programs models to serve those adults in high cost programs, including seniors. From the 15 overall projects that were funded statewide, six were senior day program demonstrations. These programs served some 250 persons at an average per diem of $21.45. A 1989 report, *New Directions for Seniors: Senior Day Program Demonstrations*, describing this initiative was issued by the OMRDD.

The senior day programs were operated both by aging network agencies and developmental disabilities providers. The programs were encouraged to admit seniors with both latelife and lifelong disabilities; however OMRDD funding was only provided for seniors with a developmental disability.

What did we learn from the demonstrations?

- that there was a market for senior retirement-oriented day programs (each quickly filled up their daily spaces and had waiting lists of persons who were referred to them);
- that a range of senior-oriented activities could be offered in a relaxed and comfortable atmosphere (daily activities included socialization, group discussions and reminiscence sessions, nutrition and health reviews, mobility and sensory stimulation, recreation and physical fitness, field trips, and personal guidance);
- that community-based facilities could be used to allow the seniors to participate in age-appropriate activities in the least restrictive setting (four of the six programs used sites that were removed from the main agency facility -- included among the sites were two churches, two special program buildings and two special program spaces within the building used by their host agency);
- that programs could enhance their normal staff when they relied heavily on volunteers (volunteers were primarily drawn from Senior Companions, Green Thumb and RSVP program participants); and
- that the programs could meet the goal of operating an integrated program (three of the programs included among their enrollees seniors who were not developmentally disabled but who had similar levels of need for supervision and program).

Other concurrent activities

During the same time period three university centers joined in the aging integration efforts undertaken by the Council, OMRDD and SOFA. These included the University of Rochester University Affiliated Program in Developmental Disabilities's (UAPDD) Training Program in Aging & Developmental Disabilities (TPADD), the Brookdale Center on Aging at

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[14] See *Standards for Social Adult Day Care*, available from the New York State Office for the Aging, Agency Building Two, Empire State Plaza, Albany, NY 12223-0001.

Hunter College and Hunter/Mt. Sinai Geriatric Education Center in New York City, and the Institute of Gerontology at Utica College.[15] Specifically:

- the University of Rochester program was instrumental in developing a network of trainers, training materials, and dissemination procedures that addressed the training and education needs of persons providing services to individuals with developmental disabilities. The University was also a recipient (since 1988) of a federal support grant from the Administration on Developmental Disabilities to operate an aging and developmental disabilities training program for service providers and for persons who are training to become service providers.

- the Brookdale Center on Aging at Hunter College, a nationally recognized center on family issues, guided the development of the New York City Task Force on Aging & Developmental Disabilities. It also received Council grants to conduct training, produce informational materials, and a training video on the effects of aging upon persons with lifelong disabilities. The Hunter/Mt. Sinai Geriatric Education Center adopted aging and developmental disabilities as one of its initiatives. This involved cross-training between the aging and developmental disabilities networks via a series of conferences and targeting staff of developmental disabilities agencies for recruitment into the GEC's educational program.

LESSONS LEARNED...

A strength of network groups is that they are composed of persons interested and committed to a particular issue. Their strength is demonstrated in how they address initiatives, develop their own training, provide technical assistance, and help educate the public at-large. Assisting such groups getting started is not hard; sometimes it only takes interest and support from governmental agencies or local providers. However, such groups rarely will coalesce unless one or several persons take on the leadership role of organizing and keeping such a group going. Like all organizations, they need a "spark" to sustain them.

- the Utica College program helped develop local provider network groups and conduct training. An associate of the University of Rochester's TPADD, it was instrumental in planning and producing the first national teleconference on aging and developmental disabilities.

At the same time, a planning group in New York City, known as the New York City Task Force on Aging and Developmental Disabilities, was asked to identify the special needs for senior services in New York City. By the mid-1989, the Task Force completed its community survey and planning efforts and requested that the Council fund a number of integration demonstration projects within New York City. It also recommended a special project to aid in the development of housing options for seniors with developmental disabilities.

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[15] Key participants at the University of Rochester effort included Dr. Philip Davidson, Jenny Overeynder and Dr. Richard Machemer. The Hunter-Brookdale/Mt. Sinai participants included Dr. Rose Dobrof, Joanna Mellor and Marilyn Howard, as well as earlier on, Dr. Meg Gold and Dr. Pat Chartock and Honey Zimmer. The Utica College participants included Dr. Ron Lucchino and Kathie Bishop.

Simultaneously, the OMRDD also issued two program development case study reports (*Sharing Activities* and *Whitehaven*) which described, respectively, the development of a program between the Oneida County ARC Seniors Program and the Cornhill Senior Center in Utica, and the development of a community residence for seniors with a model personal care component by PEOPLE, Inc., a developmental disabilities provider agency in Buffalo.[16]

On January 31, 1990 the OMRDD Commissioner and SOFA Director signed an interagency agreement binding the two agencies to cooperate with planning, financing, needs assessments, and services coordination and provision. The announcement of this agreement was circulated around the State and a request made of local administrators to undertake similar agreements at the local level (see Appendix C).

Up to the signing of the agreement, informal activities between the two agencies included reviewing and commenting on each other's state plans, exchanges of budget information, working toward an interagency memorandum of agreement, staff collaboration, joint training and education efforts, common presentations at meetings and conferences, and cooperative sponsorship of demonstration projects. The joint agency agreement served to make these activities standard practice.

The third series of demonstrations

The next demonstrations involved a special DDPC funded effort to develop new programs and increase integration activities within New York City, as well as an expansion of the State OMRDD's efforts to establish a network of senior day programs. The former effort was the direct result of a planning and service needs assessment carried out by the New York City Task Force on Aging and Developmental Disabilities. The DDPC awarded seven project grants in New York City. The projects were undertaken by both aging network and developmental disabilities agencies and were to aid in integrating seniors with developmental disabilities with other seniors and to help in developing housing options. The Task Force on Aging and Developmental Disabilities served as a facilitator and overseer for all of the projects. Projects were funded in three of New York City's five boroughs (Queens, Staten Island, and Brooklyn -- see Table 1c in Appendix A).

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[16] These two reports, *Whitehaven: Personal Care Vender Unit and Community Residence for Seniors* and *Sharing Activities: A Report on an Integration Project between the Oneida County ARC and the Cornhill Senior Center* became the models for the case study monograph series developed by the CIPADD project. Copies are available from NYS OMRDD, 44 Holland Avenue, Albany, NY 12229.

The New York City projects were different from the previously conducted demonstrations in a number of ways. Two projects in Staten Island (one, a disability agency effort to provide senior programs and the other, an aging network program to provide training) were asked to work cooperatively to aid in integrating the borough's senior programs and in setting up special programs. In Queens, the project operated by a cerebral palsy agency was to augment their existing senior program efforts by providing outreach and training to the borough's existing senior programs. In Brooklyn, three agencies (one, a Catholic services agency; another, a Jewish services agency, and the other, an agency providing a range of senior services) were asked to work cooperatively to provide outreach and training as well as drawing in seniors with developmental disabilities into their generic senior programs (including meal sites, social day care programs and senior center activity sites). An additional project was funded in Queens to identify and promote access to generic senior housing for seniors with developmental disabilities.

What did we learn from these projects? We learned that:

- interagency cooperation and intra-agency cooperation was crucial to make the integration efforts work;

- individual efforts by program managers make or break the projects; and

- targeted training was necessary to orient both agency and referral staff to aging and developmental disabilities issues and concerns.

During the same period, the OMRDD also issued a second request for proposals (RFP) designed to expand the number of projects under its State-funded senior day program initiative.[17] After a competitive review, 27 new programs (to serve some 370 additional seniors) were chosen for funding -- 14 of which were for slots within existing adult day care programs within the State's aging network. The balance were for new sites to be operated by a variety of disability agencies. (A copy of the RFP is in Appendix D.) The new senior day projects were required to:

- reflect social adult day care model practices,
- cost less than $25 per day per person,
- mix seniors with and without developmental disabilities,
- use community amenities and resources as part of the program, and
- preferably not be located in sites that serve only persons with disabilities.

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[17] The first RFP process was a call for proposals to develop new day program models for all adults. Following the selection of six programs targeted for seniors, a special marketing effort was made to develop the senior day programs into a distinct program model. This effort was particularly successful, sufficiently impressing the control agencies and the legislature that they approved an expanded effort specifically targeted for seniors. In the FY 90-91 budget, the OMRDD received new funds earmarked specifically for new senior day programs. However, because of severe budget restrictions announced in the fall of 1990, funding for these projects was deferred until July 1991.

In the fall of 1990, the funding for these projects was temporarily held up when the state budget crisis caused all works-in-progress to be deferred to the following fiscal year.

Other concurrent activities

During this period, the number of regional aging and developmental disabilities network advocacy groups increased.[18] Several of these groups sponsored conferences and other training activities on aging and developmental disabilities. Both the Oneida County Aging and MR/DD Coalition and the New York City Task Force on Aging and Developmental Disabilities set up training/colloquia series. The Oneida workshops were sponsored by a network of interested groups they called the Coalition.[19] The New York City workshops were sponsored by the New York City Task Force.

In the fall of 1990, the New York City Task Force was renamed the Council on Aging and Developmental Disabilities of Greater New York, elected leaders, and set up an operating committee structure. In addition, the Hunter-Brookdale Center on Aging produced, under the direction of the aging concerns subcommittee and with funding from the Council, a video titled *When Persons with Developmental Disabilities Age.*[20] This video presents information about the interaction of aging and lifelong disability and serves as a "trigger" video for discussions at training sessions.

As part of their commitment to providing ongoing supports, the OMRDD and SOFA provided consultation, training, and technical assistance to a variety of local providers organizations across the State. Further, the State's efforts were interwoven with those of the TPADD at the University of Rochester. The TPADD, a project funded under a grant to the university affiliated program at the University, worked closely with all facets of the

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[18] By this time a number of aging and developmental disabilities network groups had evolved, including the Western New York Consortium on Aging and Developmental Disabilities, Erie County DDPC Subcommittee on Aging and Developmental Disabilities, Monroe County Council on Aging and Developmental Disabilities, Rome DDSO Elderly Advisory Committee, Oneida County Aging and MR/DD Coalition, Southern Tier Aging and Developmental Disabilities Network, Hudson Valley - Catskill Network on Aging, Westchester Interagency Geriatrics Task Force, and (what was to become) the Council on Aging and Developmental Disabilities of Greater New York.

[19] The closure of the Rome, New York Developmental Center was a significant influence in the setting up the Coalition. Prior to closure, the Center had over 300 seniors who were part of its residual population. All of the seniors were settled in a variety of community housing options within the three county catchment area of Rome DC. Much of the credit for the work in the closure of Rome and the attention paid to developing appropriate community seniors services goes to Philip Catchpole, who was the director at Rome. He continued to serve as the director for the community based developmental disabilities services office once the Center was closed and was instrumental in supporting the work of the Coalition.

[20] The videocassette, *When Persons with Developmental Disabilities Age,* is available from the New York State Developmental Disabilities Council, 155 Washington Avenue, Albany, NY 12210.

LESSONS LEARNED

- ***it is possible to mobilize a state's natural resources to identify problems and develop practical and responsible solutions*** (initially little or no information was available that defined the population, its scope, its needs, the barriers to overcome to provide for it, and the actions to undertake);
- ***it helps to have the right people in the right places to carry out such an effort -- the "sparks"*** (leaders of the planning effort were individuals personally interested in resolving the unknowns and the identified problems);
- ***developing a planning document can be as easy or difficult as one wishes to make it*** (in our instance, it was complicated because of the numbers of people involved – however, the trade-off was a greater rate of acceptance because more sectors of the State were involved in developing it);
- ***conferences can be excellent vehicles for sharing information and developing networks*** (we purposely planned our initial conference to draw upon the native abilities found in our State's agencies and then made as much material available as possible so participants could follow-up afterwards);
- ***demonstrating that ideas and practices can work, particularly under controlled conditions, is an effective device for proving a point*** (we spent a great deal of time overseeing the demonstration projects to address problems as they came up);
- ***careful selection of demonstration sites can increase the rate of success and influence*** (the selection of demonstration sites included considerations of location, capability of the agency or persons to manage the site, and in some instances their connections with aging and developmental disabilities networks);
- ***using the "sparks" at successful demonstration sites to spread the word is very helpful*** (everyone likes to tell their peers about their successes; we encouraged the site managers to participate in conferences and workshops to spread information about what they were doing);
- ***what works in one area or milieu will not necessarily work in another*** (we found that some areas of the State have particular provider cultures and have to have their own demonstrations, not just hear about others -- so as to whet their interests);
- ***dissemination of information is crucial*** (we set up meetings and workshops in all parts of the State to "spread the word;" thus ensuring that key players heard first hand what we were doing);
- ***keep things simple and low-tech*** (we found that our efforts did not need to be complex or be based upon highly involved technology -- we let our senior day programs set their own tempo and site conditions and asked that they keep programs low cost and interesting; in return we offered them a reliable source of funds and a paper-free program model, keeping regulations out of the picture);
- ***stress the commonalities of the needs of older persons*** (we asked our programs to consider becoming community adult day care sites, open to all seniors with similar needs; we did not pay for seniors who did not have developmental disabilities, but we did not prohibit the providers from serving them);
- ***build a strong cross-training capacity*** (we found that turnover rates called for an on-going in-service or continuing education program within the community and thus encouraged our network groups and college/university affiliates to offer a variety of courses, workshops, and colloquia);
- ***keep the networks and provider groups informed*** (we found it vital to keep information flowing to the network groups and others who could affect our efforts -- the feedback to us also helped alert us of potential problems);
- ***don't be afraid to fight the battles when they need to be fought*** (sometimes we had to leverage local providers, government bodies, or survey agencies to what we were trying to do -- otherwise they would have posed a significant, albeit unintentional, barrier).

CIPADD project. In addition, the University of Rochester TPADD sponsored a series of continuing education programs and conferences.

During this period, the scope of state activities expanded broadly. Training in community integration techniques was carried out in most areas of the state. A special workgroup was formed to examine the concerns and issues related to aging and cerebral palsy and another workgroup was formed to examine aging, Down syndrome, and Alzheimer disease. A special effort was also begun to develop generic senior housing. In addition, the collective agencies hosted a national teleconference on aging and developmental disabilities.

This third phase of development activities was most valuable in making senior programs available to older persons with developmental disabilities. Indeed, over the course of the whole effort, the State witnessed a 400% increase in senior program availability as well as a range of new program models to serve seniors, both within the aging and developmental disabilities networks. This success was the direct result of an initial planning process that identified program availability, needs, and barriers, and an implementation phase that involved extensive experimentation with new approaches, community development, network building, and localized training and education efforts. Our current efforts are directed at expanding our program structures, creating a stable funding resource, and promoting individualized age-related retirement activities.

The box on page 14 offers some thoughts on the "lessons learned" from our experiences. Although in no particular order, these thoughts can serve as helpful points for discussion regarding your own efforts toward beginning or expanding community integration or program development activities. ☐

Section 2

Older Persons with Developmental Disabilities

The term *"developmental disabilities"* encompasses a variety of conditions that originate prior to or at birth or in childhood. These can include autism, cerebral palsy, epilepsy, mental retardation, learning disabilities, other similar neurological impairments, and a number of other conditions. None of these disabilities are a mental illness or disease. Instead, they constitute a lifelong cognitive or physical impairment that became apparent during childhood and has hampered an individual's ability to participate freely in mainstream society, either socially or vocationally. In addition, some people with one condition, such as mental retardation, may also be have another condition, such as seizures (epilepsy) or motor dysfunction (cerebral palsy).

One way to understand what a developmental disability is, is to think of it as a condition that an individual has had since birth or childhood -- which has prevented him or her from being socially or vocationally fully independent as an adult – and is expected to continue into old age.

Such disabilities are important to identify and understand during childhood and adolescence, since much can be done to mitigate their effects -- particularly with medical interventions or special training. With aging, such considerations are less important since the pressures of work and social competition are lessened. Longterm impairments – associated with lifelong disabilities – mirror, in many ways, the age-associated impairments that are evident in seniors with latelife disabilities.

With increasing age, a disability should be viewed within the context of the degree of impairment that is present. Consequently, information about functional abilities or level is more important than just saying that a person has a developmental disability. Experience has shown that although categorical diagnoses may serve a useful purpose for statistical reporting and planning, they are limiting as guides for service provision. This is because persons with the same categorical disability (e.g., mild mental retardation or cerebral palsy) may vary markedly in their abilities, deficits, needs and capabilities.

Such functional abilities or impairments appear similar regardless of whether the disability originated in childhood or late in life. However, there are some distinctions among ***latelife, lifelong,*** and ***midlife disabilities*** that serve to differentiate the clientele in aging and developmental disabilities network programs:

- *latelife disabilities* are conditions that occur in the later years and are often associated with the aging process;
- *lifelong* disabilities are those conditions that a person has had since birth or childhood;
- *midlife disabilities* include those conditions resulting from disease, injury, or other trauma, that cause impairment in mid-life.

Legislative definitions

To help understand the terms "developmental disabilities" and "disabilities," definitions have been provided in Federal legislation and are found under the following Public Laws:

Developmental Disabilities Assistance and Bill of Rights Act

The newest definition of developmental disabilities is embodied in Public Law 101-496, the 1990 amendments to the Developmental Disabilities Assistance and Bill of Rights Act. These amendments contain a non-categorical, functional definition of developmental disability that was revised to accommodate the inclusion of children under the age of five.

Title I, Part A, §102(5) of this Act stipulates that the term ***developmental disability*** means a severe, chronic disability of a person five years of age or older which:

- is attributable to a mental or physical impairment or combination of mental and physical impairments;
- is manifested before the person attains age twenty-two;
- is likely to continue indefinitely;
- results in substantial functional limitations in three or more of the following areas of major life activity:

-self-care,
-receptive and expressive language,
-learning,
-mobility,
-self-direction,
-capacity for independent living, and
-economic self-sufficiency; and

- reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are of lifelong or extended duration and are individually planned and coordinated
- except that such term, when applied to infants and young children means individuals from birth to age five, inclusive, who have substantial developmental delay or specific congenital or acquired conditions with a high probability of resulting in developmental disabilities if services are not provided.

Older Americans Act

The definitions of *disability* and *severe disability* that appear within §102(8)&(9) of the Older American Act Amendments of 1987 (PL 100-175) are similar in wording and purpose to other definitions of developmental disabilities.

Within the Act, the term ***disability***, is meant to include "developmental disability", "physical and mental disability", "physical and mental disabilities", or "physical disability," and is defined to mean a disability attributable to mental or physical impairment, or a combination of mental and physical impairments, that results in substantial functional limitations in one or more of the following areas of major life activity:

- (A) self-care,
- (B) receptive and expressive language,
- (C) learning,
- (D) mobility,
- (E) self-direction,
- (F) capacity for independent living,
- (G) economic self-sufficiency,
- (H) cognitive functioning, and
- (I) emotional adjustment.

The term ***severe disability*** is defined to mean a severe, chronic disability attributable to mental or physical impairment, or a combination of mental and physical impairments, that--

- (A) is likely to continue indefinitely; and
- (B) results in substantial functional limitation in three or more of the major life activities specified in the (A) through (G) above.

Age definitions

When should we consider a person as "aged," "old," or "elderly?" There is substantial disagreement among social gerontologists about what chronological age defines "old," "older," or "elderly" (see the table on page 20 for definitions of aging terms). Social convention about what is "old" has changed as life expectancy has increased. Certainly, the expectations of aging that were prevalent at the turn of the century are not the same now when average life expectancy is well into the 70s. Further, the concept of the "Third Age" (i.e., that period of life following retirement, but prior to infirmity, generally characterized by good health and free time to pursue leisure and avocational endeavors) bears evidence for the healthiness and independence of many older persons.[1]

Gerontological definitions of aging can be viewed from three perspectives linked to functional aging. Each of the following could be used to define old age; however, for each there is also a reasonable counter-argument that mitigates its sole use. These perspectives note that:

- for *biological aging*, which is an individual's progressive loss of physiological reserves, we find that defining aging only in terms of biological aging is confounded by the substantial differences among people in terms of how and when they each physically age.
- for *psychological aging*, which consists of changes in a person's adaptive capacities, we find that many people do not perceive themselves as old or elderly even when their chronological age equates stereotypical old age.
- for *social aging*, which is the extent to which an individual fulfills the expected social and cultural roles, we find that even with social roles, many older persons do not conform to societal expectations of what constitutes behavior or role expectations among the elderly.

Legal definitions of aging relate entitlements to benefits or changes in life status -- such as retirement -- to chronological aging. Such linkages are based upon historical practices and societal perceptions of old age. Retirement, for example, in most instances was mandated at age 70; however, such age discrimination is now generally forbidden by federal law (cf., Age Discrimination in Employment Act of 1967[2]). Social Security benefit agelines, traditionally began at age 62 or 65; although, these too are becoming more flexible as government officials look for expense-cutting mechanisms in financially tight times (such as, recurring proposals for raising the eligibility age for Older American Act services and enacted legislation raising the age for receipt of Social Security benefits).

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[1] For a more detailed explanation of the definitions of aging see *Contemporary Issues in the Aging of Persons with Mental Retardation and other Developmental Disabilities* (M.P. Janicki, M.M. Seltzer, & M.W. Krauss), A Rehabilitation Research Review available from the National Rehabilitation Information Center, 8455 Colesville Road, Suite 935, Silver Spring, MD 20910. Also see M.M. Seltzer and M.W. Krauss, *Aging and Mental Retardation: Extending the Continuum*, available from the American Association on Mental Retardation, 1719 Kalorama Road, N.W., Washington, DC 20009.

[2] For information on the ADE Act see *The Age Discrimination in Employment Act guarantees you certain rights. Here's how....* available from the American Association of Retired Persons, 1909 K Street, N.W., Washington, DC 20049.

SOME COMMON AGING TERMS[3]

- *Age*
  One of the stages of life; an advanced stage of life; the latter period of life; the state of being old; to become old; to show the effects of the characteristics of increasing age.
- *Aged*
  The state of being old; a person may be defined as being aged on the basis of having reached a specific age – for example, 65 is often used for social or legislative policies, while 75 is used for physiological evaluations.
- *Ageism*
  Prejudice against people because they are old; attitudes that devalue older people
- *Aging*
  The changes that occur in persons as they grow older; aging is a developmental process that begins at conception and continues until death; such changes can involve biological, social or psychological changes and can occur at varying rates in different people.
- *Chronological age*
  An individual's numerical age dating from the time of his or her birth.
- *Elder or elderly*
  Generally referring to individuals over age 60.
- *Functional age*
  An assessment of age based upon physical or mental performance rather than number of years since birth.
- *Frail elderly*
  Elderly person whose physical and emotional abilities or social support system is so reduced that maintaining a household and social contacts is difficult and sometimes impossible, without regular assistance from others.
- *Gerontology*
  This is the study of aging, and includes all the arts and sciences which contribute to our understanding of age-related changes of human function.
- *Geriatrics*
  This is the branch of medicine in which the social, psychological and clinical aspects of disease in old age, as well as the care of older persons are studied.

The difficulty with applying these types of definitions of aging to older individuals with mental retardation or other developmental disabilities illustrates why most of the literature on aging and developmental disabilities has relied solely on a chronological definition of old age. But even here, there is a lack of consensus among mental retardation and developmental disabilities professionals as to what age constitutes the beginning of old age for this group. Examinations of published research studies and reports (such as those reported by Seltzer and Krauss, 1987) have shown the definition of "old age" for this population to range between 40 and 75 years of age. Ages used by public agencies show similar variability. A survey of state developmental disabilities planning councils and state units on aging found that the ages they used ranged from age 55 to 65. Such numerical variables contribute to a lack of uniformity among gerontologist as to what age constitutes "elderly."

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[3] These definitions were taken from *Glossary of Important Terms, Concepts, and Resources in the Fields of Aging and Developmental Disabilities*, published by the Council on Aging and Developmental Disabilities of Greater New York (October, 1990); it is available from the Hunter-Brookdale Center on Aging, 425 East 25th Street, New York, NY 10010. See also *Age Words: A Glossary on Health and Aging*, available from the National Institute on Aging, National Institutes of Health, Bethesda, MD 20892.

Similar arguments can be made for defining old age among persons with developmental disabilities. Although some workers have tried to define old age among persons with developmental disabilities based upon the same means noted above, they have not held up due to individual variations in the aging process. The reasons for the widely varying base age for defining old age among individuals with developmental disabilities include evidence that:

- some persons with developmental disabilities begin to experience decline in behavioral capabilities in their 50s,
- there is evidence of precocious physical aging (along with an increased incidence of Alzheimer's disease) among persons with Down syndrome -- a major sub-group within the population of persons with mental retardation, and
- persons with certain developmental disabilities have historically had a shorter average lifespan than their age peers in the general public.

However, due to the heterogeneous nature of individuals with mental retardation and other developmental disabilities and to recent indications of greater longevity, these three trends are each applicable to some persons with developmental disabilities, but not to all.

The inclusion of specific provisions for older persons with disabilities in the 1987 reauthorization of the Older Americans Act of 1965 (PL 89-73, as amended) may eventually lead to definitional consistency by the public sector. The Act specifies age 60 as the age of eligibility for services and requires equal access to services by older individuals with disabilities. However, many workers recognize that premature or precocious aging is a major concern among certain persons with developmental disabilities, as it is among other older persons who age prematurely. Thus, there is a need to plan for these older populations and the problems posed by individuals with developmental disabilities who age prematurely. We will need to consider the use of a younger age (possibly 55 as recommended by Seltzer and Krauss in *Aging and Mental Retardation*; 1987) for definitional purposes and provision of compensatory services. The consideration of a lower age permits both the inclusion of persons who have aged prematurely and those whose aging or senior service needs should be considered within the next five to ten years.

Presently, planning for age-related services for older persons with a developmental disability has become more coincident with the eligibility age of the Older Americans Act (that is, age 60).[4] Additionally, when identifying needs associated with sub-groups of the older population, it is helpful to think of older age categories that are associated with noted changes in needs or services. Using age 60 as a reference point, the following categories, prevalent in the field of gerontology, can also be useful in planning for older persons with developmental disabilities:

- Late middle age 50 - 59 years of age
- Young-old: 60 - 74 years of age
- Mid-old: 75 - 84 years of age
- Old-old: 85 years and up

Aging and lifelong disability

Most research data available in the area of aging and developmental disabilities are limited to studies involving persons with mental retardation. Thus, most of the information available involves this condition. In terms of decline associated with aging, the differences observed are generally a function of level of mental retardation and whether the retardation is the result of genetically or environmentally related delayed development or organically derived mental deficiency. Indications are that individuals with mild and moderate impairments evidence more marked, albeit normative, decline, while individuals with severe and profound impairments show minimal decline. It appears that "the more you have, the more you lose."

It has been reported that decline generally is evident earlier in certain behavioral areas; for example, gross motor and overall independent functioning abilities appear to decline in the mid-50s. Other skill areas, such as basic activities of daily living and cognitive skills, show decline beginning in the mid-70s. Such decline patterns, however, are particular to each older individual.

Contrary to some beliefs, persons with mental retardation do not normally age more rapidly than peers of the same cultural or socioeconomic background. One major exception is that persons with Down syndrome appear to age earlier (up to possibly two or three decades) and appear to suffer a greater co-incidence of Alzheimer's disease. Precocious or early aging occurs in the fourth decade and about one of three older persons with Down syndrome show symptoms indicative of Alzheimer's disease (usually by the mid-50s).

What is known about the effects of age upon persons with other types of disabilities? Experience or information in the literature shows us the following:

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[4] With certain exceptions, statutory eligibility for services under the Older Americans Act is set at age 60. The exceptions include employment programs where the age is 55, and nutrition site participation where adults under age 60 may be served if they are a spouse, reside in a congregate care site where there is a meal program, or when they are a person with a disability and accompany an eligible senior who provides for his or her care.

- ***Autism:*** it is rare to see a person diagnosed with this condition in old age since there is a "mellowing effect" of the symptoms during mid-life; that is, the most pronounced childhood dysfunctions become less prominent with age. Most older persons with autistic behaviors may be considered to be mentally retarded in old age, particularly if mental retardation was co-incident. Others may be classified under a psychiatric category, such as childhood schizophrenia. Otherwise little else is known about the interaction of aging and autism.

- ***Cerebral palsy:*** little is known about the interaction of aging and cerebral palsy with the exception that with advancing age, there are more men than women (that is, there appear to be more longterm survivors among men than women).[5] Physically, because of a lifetime of muscular dysfunction, age appears to have a much more deleterious effect on ambulation and other movement functions. Many older persons with cerebral palsy appear to lose muscular abilities sooner than other age peers. The co-prevalence of arthritis among older persons with cerebral palsy is also reported.

- ***Epilepsy:*** little is known about the interaction of aging and seizures over a lifetime. Population studies appear to indicate a shorter life expectancy, particularly among those individuals with severe forms of epilepsy and multiple disabilities (such as epilepsy and mental retardation).

- ***Learning disabilities:*** the lifetime effects of a learning disability may be seen in a senior's continued inability to read, write, or readily recognize symbols. Little is known about other particular effects of aging.

- ***Sensory disabilities*** *(i.e., blindness or deafness):* sensory disabilities may compromise independent functioning, and this may become compounded for persons for whom this has been a lifelong dysfunction.

- ***Other disabilities:*** the disability with most anecdotal information is post-polio syndrome. Muscular dysfunction appears to be aggravated by the aging process and premature limitations of mobility has been noted among older adults. Another condition with some anecdotal information is traumatic brain injury; it has been noted that precocious aging may occur among some older individuals with head injury. Indeed, most conditions resulting from severe neurological damage or musculoskeletal dysfunction appear to be more markedly affected by the physical aging process.

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[5] See the report, *Cerebral Palsy and Aging*, available from the New York State Developmental Disabilities Planning Council, 155 Washington Avenue, Albany, NY 12210

Estimating the numbers of older persons with a developmental disability

The character of the nation's demographics is showing a marked bulge among persons currently in their 30s and 40s (the "baby boomers;" that is, those persons born shortly after World War II and into the mid-1960s). This has contributed to a growing number of persons in the middle age group. Demographers portend a major shift in the character of the population over the next twenty years as this group ages. The aging of this generation will create a population surge resulting in a "senior boom" generation, which will peak in numbers by 2035. The same changes will affect today's population of persons with developmental disabilities. For example, some estimates show that for every older person with a developmental disability in senior services today, two to three additional seniors will be seeking senior services within the next ten to fifteen years.

The 1990 population census has revealed that there are approximately 248 million Americans, some 17% of whom are age 60 or older. Early reports show a dramatic shift in the proportional location of our population, with the South and sunbelt states showing the greatest growth and the North and Midwest showing the least change. Many of those persons left in the North, Midwest and Central regions will increase the proportion of the state's population that is elderly.

Demands upon the nation's services for elderly persons will be in large part determined by today's baby boom generation. Much of the increased demand will be evident in the decade following the year 2000, when the first wave of the baby boomers will begin to enter the younger-senior age group. Consequently, current planning for changing needs over the next ten to fifteen years is critical if appropriate services are to be provided.

ESTIMATING NUMBERS

A rough rule of thumb in determining how many persons may be living in any particular state or region is that at least 4 out of every 1000 older persons is an individual with a developmental disability. For example, in a community with an overall population of some 100,000 persons, some 17% of whom are 60+, then a rough estimate is that there may be about 70 older persons with a developmental disability. Or, in a metropolitan area with some 2.5 million persons, 9% of whom are age 60+, then the expectation is that there will be some 890 older persons with a developmental disability. Please keep in mind that this estimated frequency is not adjusted for local demographic variations or mortality trends.

Historically, persons with severe developmental disabilities had been considered to have relatively short life expectancies. In addition, in the past older adults with developmental disabilities spent much of their lives in public institutions. These factors contributed to the lack of awareness or concern for older and elderly adults with developmental disabilities. With improved social conditions, medical care and programmatic technologies, persons with such disabilities are now living longer. Thus, greater longevity of persons with developmental disabilities, the overall growth of the general population, and the greater number of individuals with lifelong disabilities residing in community settings, have heightened awareness that there will be a greater demand for services. Further, as a result of deinstitutionalization efforts over the past 15 years and an increased emphasis on community living programs, more older adults with developmental disabilities are visible and present in our communities; an increasing number of whom are residing with their elderly parents, other relatives or with spouses. These factors have all contributed to a greater awareness of a need to arrive at informed estimates of the number of older persons with a developmental disability.

Although no definitive demographic studies have been undertaken, current population estimates are that there are between 200,000 and 500,000 older persons with a developmental disability in the United States and between 13,000 and 30,000 such persons in Canada. Conservative estimates indicate that typically older adults with developmental disabilities account for about four out of every 1000 older individuals in any community. The box on page 24 contains examples of how to apply this rule of thumb to your area.

The appendix contains a series of tables that can serve as aids to estimating your state's population of older persons with developmental disabilities. This census-based information, provided by the federal Administration on Aging, can be useful in projecting the potential impact of the growth of your state's older population (both with and without developmental disabilities). The developmental disabilities data can be useful in state and local planning efforts when establishing a baseline for developmental disabilities population estimates. The developmental disabilities population data are based upon an assumption that about four of each 1000 elderly persons is an individual with a developmental disability. Should you wish to use a different assumption for your planning, the numbers should be adjusted accordingly.

Preliminary 1990 Census information indicated that there were 248,709,873 residents of the United States; however, no age specific information was released at the time this manual was prepared. Thus, the tables in the Appendix are drawn from adjusted US Census information for 1989 that contained population expectations for various age groups. The information contained in the tables may change with the publication of 1990 age specific groupings. Readers are advised to check with their state's office which distributes official census information (or the Administration on Aging) for the most recent figures.

The following tables are found in Appendix B:

- Table 2a gives the provisional estimate of the number and percentage of older persons in each state, age 55+, 60+, and 65+.[6]
- Table 2b gives the number and percentage of persons age 60+, by state, currently and the projected number and percentage of persons age 60+ for the years 2000 and 2010.
- Table 2c gives the number of persons age 60+, 65+, 75+ and 85+ and percentage of older persons over age 60+ within older age groups by state.
- Table 3 gives the number of individuals, by state, who are age 55+ and 60+, and the expected number of persons with a developmental disability age 55+ and 60+ within each state.[7] □

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[6] These tables are drawn from U.S. Administration on Aging Information Memorandum #AOA-IM-90-19 (Estimates of the Number of Older People by State: 1989); the author is Donald G. Fowles of AoA.

[7] Since the basic eligibility requirement for services under the Older Americans Act is being age 60 or older, this age is used throughout this manual in order to provide consistency in planning. The 0.396% prevalence rate used is taken from Jacobson, J.W., Sutton, M. & Janicki, M.P., "Demography and characteristics of aging and aged mentally retarded people", in M. Janicki and H.M. Wisniewski (eds.), *Aging and Developmental Disabilities: Issues and Approaches*, Paul H. Brookes Publishing Company, Baltimore, MD, 1985.

Section 3

Legislative Supports

Important legislative supports have been passed by the U.S. Congress that include provisions on aging and developmental disabilities. These include:

- Developmental Disabilities Assistance and Bill of Rights Act,
- Older Americans Act,
- Public Health Services Act,
- Americans with Disabilities Act,
- Domestic Volunteer Services Act, and
- "Nursing Home Reform Act."

The following abstracts contain legislative provisions which provide support in the area of aging and developmental disabilities.

Developmental Disabilities Assistance and Bill of Rights Act

The most important changes related to aging concerns in the Developmental Disabilities Assistance and Bill of Rights Act occurred in the 1987 amendments to the Act (P.L. 100-142). The changes included the following:

- developmental disabilities councils are required to review and comment on the state aging plan (prepared by the state unit on aging[1]);

- the state unit on aging is required to be included as a member of the state developmental disabilities planning council; and

- legislative mandate and funding was provided for the training of personnel in programs for elderly persons with developmental disabilities. Specifically, the legislation calls for the Administration on Developmental Disabilities to provide support to university affiliated programs (UAPs) for planning, designing, and implementing coordinated interdisciplinary training programs between existing aging or gerontological programs in conjunction with the UAPs to prepare staff for providing services to elderly persons with developmental disabilities.

- authorizing a new provision in §152 of the Act, Congress intended to encourage the development of a series of university-based training centers that would substantially increase the available pool of workers trained to work with elderly persons with developmental disabilities. Further, the intent was to encourage the pairing of existing programs in developmental disabilities with existing programs in gerontology or geriatric medicine.

The 1990 Amendments to the Developmental Disabilities Assistance and Bill of Rights Act continued authority for these activities. Although the structure of the funding for core activities at the university affiliated programs was changed, the provisions of §152 with regard to aging training centers were retained. The 1990 amendments also recognized the importance of *interdependence*, a critical feature of programming at senior programs.[2]

Older Americans Act[3]

Several changes in the 1987 amendments to the Older Americans Act (PL 100-175) address disability, particularly the language that was revised to include older persons with disabilities in mainstream services provided under the Act. Other specific changes included:

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[1] For the sake of convention, the term *state unit on aging* will be used to refer to the state aging departments, offices, councils, bureaus, etc., mandated by the Older Americans Act. For information on your state unit on aging, contact the National Association of State Units on Aging, 2033 K Street N.W., Suite 304, Washington, DC 20006.

[2] For more information on provision of the Act, contact your state developmental disabilities planning council. A list of state councils is available from the National Association of Developmental Disabilities Planning Councils, 1234 Massachusetts Avenue, N.W., Suite 103, Washington, DC 20005; telephone 202/347-1234.

[3] For a comprehensive description of the history and workings of the Older Americans Act, see *An Orientation Manual to the Older Americans Act*, by Susan Coombs Ficke. It is available from the National Association of State Units on Aging (2033 K Street, N.W., Washington, DC 20005; telephone 202/785-0707). Readers are also advised to check your state unit on aging for the most up-to-date information.

- encouraging the state unit on aging and the area agencies on aging and state and local mental retardation/ developmental disabilities agencies to cooperatively plan and develop services for older persons with developmental disabilities;
- allowing disabled, dependent adults under the age of 60 are able to be served at congregate meal sites when accompanying their eligible parent or caregiver;
- authorizing the Commissioner of the Administration on Aging (AoA) to make grants for the preparation of personnel in the field of aging, or those preparing to enter the field of aging, and give special consideration to those individuals preparing for employment in that part of the field of aging which relates to providing services to individuals with disabilities; and
- authorizing the Commissioner to offer a grant to establish or maintain a multidisciplinary center of gerontology or a gerontology center with special emphasis on "disabilities (including severe disabilities)."
- establishing a linkage between the long-term care ombudsman program within the state unit on aging and the protection and advocacy agency within the state.

Public Health Service Act

The 99th Congress produced legislation authorizing the training of geriatricians in areas of aging and mental retardation.[4] This legislation is directed toward physicians, and has applicability to those UAPs located in, or affiliated with, medical schools. P.L. 99-660 (Title VI - Geriatric Training), which amended Section 788 of the Public Health Service Act, calls for

- the Secretary of the Office of Human Development Services to make grants to schools of medicine, teaching hospitals, and graduate medical education programs to provide support for geriatric medicine training projects that would produce more geriatricians; and
- such projects to provide training in geriatrics and exposure to the physical and mental disabilities of elderly individuals through a variety of service rotations, including community care programs for elderly individuals with mental retardation.

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[4] For more information about this program, contact the Project Coordinator, Health Resources and Services Administration (HRSA), Facility Training Project in Geriatric Medicine and Dentistry, Division of Medicine, Parklane Building, 5600 Fishers Lane, Room 4304, Rockville, Maryland 20857; telephone 301/443-5794 or 301/443-3614.

Americans with Disabilities Act

The 101st Congress passed the Americans with Disabilities Act of 1990 (P.L. 101-336). Title III of the Act prohibits discrimination against individuals with disabilities in the full and equal enjoyment of goods, services, facilities, privileges, advantages, or accommodations of any place of public accommodation.[5] These provisions:

- as defined in §301(7)(K), include a range of amenities or places of services, including senior citizen centers, day care sites and social services centers; and
- as defined in §302(2)(A), state that no places shall discriminate by the imposition of eligibility criteria for the use of services, failure to remove architectural barriers, maintenance of policies or practices that impede accessibility, and other aspects that demonstrate willful discrimination of person with disabilities.

Domestic Volunteer Service Act

The 101st Congress reauthorized P.L. 93-113, the Domestic Volunteer Service Act, originally passed in 1973.[6] The Act covers a number of older American volunteer programs including Foster Grandparents, RSVP, and Senior Companions. Although the primary purpose of the Act's Senior Companion component is to assist elderly persons who are home-bound, the Act also authorizes senior companions to assist adults with a developmental disability in any situation. Provisions include:

- allowing any eligible agency or organization wishing to sponsor a Senior Companion Project without ACTION funding to enter into a Memorandum of Agreement with ACTION; such a memorandum would permit the sponsor to maintain a senior companion program and enable the seniors, who serve as volunteers in the program, to maintain a tax-exempt status for allowable federal benefits.
- permitting any public agency or private non-for-profit organizations wishing to sponsor a Senior Companion Project with ACTION funding to apply for ACTION grant funds.
- identifying eligible volunteers as persons, age 60 and older, who meet the income eligibility guidelines of ACTION (current

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[5] For more information on how the Act applies to persons with developmental disabilities, contact your state protection and advocacy agency. For a list of state protection and advocacy agencies, contact the National Association of Protection and Advocacy Systems, 300 I Street, N.E., Suite 212, Washington, DC 20002; telephone 202/546-8202.

[6] The program is administered by the federal ACTION agency. For information, contact ACTION, Senior Companion Program, 806 Connecticut Avenue N.W., M-1008, Washington, DC 20525; telephone 202/634-9349.

regulations call for being within 125% of DHHS poverty income guidelines).

"Nursing Home Reform Act"

In 1987, Congress passed the "Omnibus Budget Reconciliation Act of 1987 (P.L. 100-203), which is commonly referred to as OBRA-87. A segment of this encompassing legislation contained a series of provisions designed to reform the nursing home industry in the United States (it is often referred to as the "Nursing Home Reform Act"). Section 1919(e)(7) of the Social Security Act was amended via OBRA-87 to institute new procedures for the admission and retention of persons with mental retardation or other developmental disability in nursing facilities.[7]

Specifically:

- establishing a mandate for the preadmission screening of every person with a developmental disability prior to admission to a nursing facility;
- establishing a mandate for the annual review of every person with a developmental disability residing in a nursing facility; and
- establishing a mandate that persons with a developmental disability found to be inappropriately placed into and remaining in nursing facilities be discharged; those who can remain, if not exempt for specific reasons, are to receive specialized services to address their particular needs related to their developmental disability. □

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[7] The best resources for information on this legislation and its most recent provisions are a series of publications issued by the National Association of State Mental Retardation Program Directors (contact NASMRPD at 113 Oronoco Street, Alexandria, VA 22314; telephone 703/683-4202 or fax 703/684-1395). For more general information, contact the National Citizens' Coalition for Nursing Home Reform, 1424 16th Street, N.W., Suite L2, Washington, DC 20036; telephone 202/797-0657.

Section 4

Identifying Barriers to Integration

Generally barriers to integration efforts can be found within one or more of the following categories:

- policy
- attitudinal
- information/communication
- financial
- coordination/administrative
- programmatic
- education/training

The sections that follow summarize a number of key barriers and offer a series of ideas and questions about how to identify such barriers in your state.[1]

Policy barriers

Policy barriers generally reflect inactivity, unresponsiveness or counterproductive actions on the part of governmental bodies or agencies.

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[1] Substantial portions of the matter in this and the following section first appeared in *Barriers and Strategies: Barriers and Strategies for the Integration of Older Persons with Developmental Disabilities* Within Aging Network Services (New York State Office for the Aging, Albany, NY 12223), published in 1987. I-Hsin Wu was the principal author.

Many of the barriers that were first identified by the report *Barriers and Strategies* in the late 1980s, related to aging and developmental disabilities have to some degree been resolved. However, others have yet to be resolved. For example, an early 1980s survey of how well state developmental disabilities and aging plans addressed the needs of their state's older persons with developmental disabilities found that few state plans made specific mention of this target population. However, in the intervening years, much has happened across the nation.

A significant amount of what has happened can be attributable to the intiatives of the federal agencies responsible for the Developmental Disabilities Assistance and Bill of Rights Act and the Older Americans Act (that is, the Administrations on Developmental Disabilities and Aging within the federal Office of Health and Human Services). One of the initiatives was the issuance of a joint agreement on how to approach this population; another was the support of university based training centers.

At the state level, a number of state mental retardation/developmental disabilities agencies have begun to address this area. Some have held networking conferences, established policies on aging, designated key program development staff, and developed program models to serve older persons with developmental disabilities.

> *"The principles – independence, dignity and value – are just as important for older persons with a developmental disability as they are for any other older individual. Thus, efforts must be made to eliminate artificial barriers that restrict the access of older persons with a developmental disability to the services they need and deserve. Further, unless the barriers noted above are addressed, successful integration can not be achieved. The challenge, therefore, is to devise strategies which will reduce or eliminate barriers and facilitate the physical and social integration of all persons with handicapping conditions, including those with developmental disabilities, within the mainstream aging network programs and services."*
> Source: Barriers and Strategies

An additional factor was the adoption by state agencies of a statement of principles affirming the basic rights of older persons with developmental disabilities. Such basic rights must include an affirmation that all elderly people have an equal opportunity to participate in the activities in which they chose to be involved, that all elderly persons have the right to be integrated with peers, and that services obtained should be provided in a manner that is flexible, accessible, and appropriate and that promotes the dignity of the individual.

In addition, interest was and has been continued to be shown by a variety of national groups. The National Association of State Units on Aging passed a resolution requesting directors of state units to seek to work cooperatively with their counterparts administering mental retardation/developmental disabilities agencies. The National Association of Area Agencies on Aging distributed background materials on aging and developmental disabilities to its membership. Support for state activities also was shown by the National Council on the Aging, the National Association of State Mental Retardation Program Directors, and the National Association of Developmental Disabilities Councils.[2]

However, in spite of this growing activity, there is still a noticeable lack of commitment to policy development in many states. This lack of commitment is most problematic since both the aging and developmental disabilities systems in large part rely on state monies to develop and sustain new program efforts. Further, the knowledge that the numbers of older persons with developmental disabilities will only increase, calls for attention by policy makers.

☐ ***Identifying policy barriers***

- ☐ *determine if your state has a policy regarding rights and services for older adults with developmental disabilities.*
- ☐ *determine whether the state plans of the state developmental disabilities council, the state unit on aging, and -- if required -- the state developmental disabilities agency address aging and senior services for persons with lifelong disabilities.*
- ☐ *review the policies of state associations (such as the Association for Retarded Citizens), the state adult day care providers, the community residence administrators, and the like and determine whether or not they address serving older adults with developmental disabilities.*
- ☐ *review your state law -- does it contain any statutes that are direct impediments to free and equal access of senior services by older adults with developmental disabilities?*

Attitudinal barriers

Attitudinal barriers can be found among:

- aging network providers,
- developmental disabilities providers,
- older persons with a developmental disability and their families, and
- elderly persons in the general population.

Attitudes among aging network providers

The attitudes of some aging network personnel can pose a barrier. For example, they avoid becoming involved in addressing the problems of older persons with developmental disabilities because they often overestimate the difficulties of dealing with the problems these individuals may have. Some aging network personnel have attitudinal problems characterized under the rubric of "handicapism" and may view all levels of disability as being the same.

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[2] Addresses and telephone numbers of these associations are given in Appendix E.

Many aging services providers are afraid that they would not know how to provide special services to someone with a developmental disability. They express concern that they would not know what to do in the event of a seizure, or if the disabled person begins to act "strange." They also fear that the inclusion of persons with developmental disabilities may upset their regular clientele.

Attitudes among developmental disabilities providers

Some developmental disabilities system personnel tend to be overprotective, thus restricting opportunities for older persons with a developmental disability. Some service providers feel that "we can do it better than anyone else," and ignore the potential benefits that integration may bring for an older person with a developmental disability.

Moreover, the lack of recognition of needs and services for informal caregivers is also an attitudinal problem. There is a clear need for the provision of supportive services to help families cope with the increasing needs of older and elderly dependents with a developmental disability.

DISABILITIES SYSTEM PROGRAM BARRIERS

- ***territoriality*** *- when developmental disabilities agencies and providers believe that they must do all for their older clientele, because, "they are our responsibility." This barrier is evident when working with the aging network is dismissed outright due to a belief that the sole responsibility for providing services lies with the developmental disabilities agency.*
- ***elitism*** *- when the developmental disabilities agency contends that its services or those generally available within the developmental disabilities system are grossly superior to any available within the generic aging network. It is characterized by the attitude, "we can do it better," so why look to what is available in the aging network.*
- ***denial*** *- when agencies and providers have not yet come to grips with the special needs posed by the population of their older and elderly clientele, nor recognize the possible size and scope of the population. This barrier is evident, when contrary to reality, there is a denial of interest. The feeling expressed here is "it's not a special concern and we need not attend to it."*

Attitudes of older persons with a developmental disability and their families

Some attitudinal barriers relate to the reluctance by the families (for example, parents or caregivers) of older persons with a developmental disability living in the community to use the formal developmental disabilities system. Often they are elderly parents or other caregivers who had their families at a time when persons with developmental disabilities were regularly institutionalized; the only other option was to keep their disabled child at home. Consequently, many parents fought the system to keep their dependents at home. Some continue to fear the formal service system because of their early and "bad" experiences with it.

For older persons with a developmental disability, fear of change, loss of current friends, and fears of going out alone are factors in their reluctance to participate in aging network programs.

In addition, some older persons with a developmental disability communicate and express their needs with difficulty and may feel very much isolated in a new setting. Very few older persons with a developmental disability are experienced in taking an active role in making decisions affecting their lives. Because they generally have learned to be passive in the presence of authority figures, the freer environment of senior sites may be problematic and cause them to become anxious about what to do and how to act.

AGING NETWORK PROGRAM BARRIERS

- ***"handicapism"*** *- negative attitudes that are expressed by officials, administrators, and other older persons toward individuals with a disability; this attitudinal bias manifests itself by these individuals not wanting the person who is disabled to use their services or to be in their program.*
- ***economics*** *- when the limited monies available to groups that provide mandated services for persons who are elderly are used as an excuse not to serve seniors with disabilities. Officials and administrators may resent having to spend these limited monies when the group having primary responsibility for persons with developmental disabilities should, in their thinking, be spending its own monies on older persons with developmental disabilities.*
- ***inexperience and lack of understanding*** *- when staff working in a program serving older individuals do not know how to respond to a person with a developmental disability. Sometimes based in reality, as staff working with seniors are rarely trained to serve persons with developmental disabilities. As a consequence, they may overestimate the extent of problems they may face and not want to admit an older person with a developmental disability into their program.*

Attitudes among elderly persons without lifelong disabilities

Perhaps the greatest attitudinal barrier to integration is that many persons, including older persons, have negative stereotypes about developmental disabilities and about older persons with a developmental disability. Although, neither the older person with a developmental disability nor the elderly person without a developmental disability are accorded valued roles by our society, seniors with a developmental disability are particularly susceptible to being negatively stereotyped. They are subjected to prejudices resulting from the common assumptions that they are child-like, have maladaptive behaviors, and look disabled.

Thus, elderly persons may be reluctant to share common services with aged peers who have a developmental disability. The reluctance can be attributed to several factors:

- the stigma of disabilities can be particularly threatening to older persons who are anxious about their own cognitive capacities and ability to function competently;
- older persons may have grown up during a time when persons with mental retardation and developmental disabilities were much

more severely devalued than they are today; and

- the lack of exposure to older persons with a developmental disability in every day life contributes to a poor understanding of these persons.

In reality many older persons with a developmental disability are relatively capable and independent, able to communicate, do not have maladaptive behaviors, are in good health and are not particularly different in appearance from other seniors.

☐ ***Identifying attitudinal barriers***

- ☐ *look for written or spoken discrimination about persons and/or older persons with disabilities.*
- ☐ *look for disability agencies policies that preclude outside involvement of the persons they serve*
- ☐ *look for reticence on the part of provider agency boards of directors or parents to expose their clientele or sons/daughters to community senior programs*
- ☐ *look for reluctance of disability agencies to make referrals to integration programs*
- ☐ *look for wording in state and disability council plans that may not encourage integration.*
- ☐ *look for efforts by the state unit on aging to ensure free and equal access to senior program sites by all minority populations.*

Information/communication barriers

This barrier encompasses a number of areas where the lack of information inhibits effective integration and services. For example, the lack of available information about older persons with a developmental disability who live in the community and are unknown to the formal developmental disabilities system may exacerbate the problem of changing the caregiver situation. As adults with developmental disabilities living in the community get older, their parents and other caregivers also age and eventually will be unable to provide care. If they are unknown to agencies that have community care resources, the care patterns for such adults with developmental disabilities may be radically altered and precipitate trauma and crises when institutional placement is sought unnecessarily by health agencies or remaining family members provide care.

Another major barrier is related to the lack of communication among service agencies. Systems serving aging persons and persons who have a developmental disability have historically been separate and independent. The two networks seldom provide services at the same setting and rarely establish formal channels of communication. Although both networks provide a wide array of similar services, neither one knows much about the other. This lack of knowledge interferes with their ability to help their older clientele.

Confidentiality of records is also seen as a barrier impeding the delivery of services. If records could be shared, the time and money needed to generate duplicate records could be saved for both the providers and the service's consumers. In addition, a lack of a comprehensive intake and referral system in most communities that integrates information from all the service systems may also impede coordination and utilization of generic aging services by older persons with a developmental disability.

Another barrier is linked to some local services providers who either misunderstand the regulations or lack information concerning requirements and regulations for serving older persons with a developmental disability. This creates unnecessary deterrents in extending aging services to older persons with a developmental disability. For example, the application for senior programs of the 1988 federal Medicaid regulations for the intermediate care facilities for persons with mental retardation (ICF-MR) program[3] has not always been clearly communicated to developmental disabilities agencies.

Many persons are not aware that the interpretative guidelines of these regulations now support the position that aging is not a barrier to the continued receipt of services in an ICF-MR. Further, no discriminants are built in that would restrict

AGING RELATED GUIDELINES TO THE ICF-MR REGULATIONS

The guideline for standard W180 (concerning types of disciplines included under "human services professionals") includes the academic discipline of gerontology [Reference: 483.430(b)(5)(x)].

The guideline for standard W196 (concerning the definition of active treatment) includes an elaboration of the applicability of active treatment for elderly persons and states: "...active treatment for elderly individuals may increasingly need to focus on interventions and activities which promote physical wellness and fitness, socialization and tasks that stress maintaining coordination skills and reducing the rate of loss of skills that accompanies the physical aspects of the aging process." Further, the guideline states, "Surveyors must be sensitive to the total life span context when they review elderly individual's unique needs" [Reference: 483.440(a)(1)(ii)].

The guideline for standard W211 (concerning the comprehensive functional assessment) notes that "the active treatment assessment process should be sensitive to the behaviors of individuals throughout their life span. For example, ...elderly citizens are expected to choose whichever form of productive activity meets their needs and interests (employment, handiwork, pursuit of leisure, etc.) for as long as they are able" [Reference: 483.440(c)(3)].

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[3] The Intermediate Care Facility for the Mentally Retarded (ICF-MR) program is a federally supported program for a class of health related facilities specifically designed to provide housing and special services for persons with mental retardation and related conditions. States participating in this program are able to receive federal financial participation via the Medicaid program administered by the Health Care Financing Administration (HCFA). In 1988, the HCFA issued a set of Interpretative Guidelines to accompany the regulations governing the ICF-MR program. These standards are used in surveys that examine state compliance with the regulatory requirements for participation in the program. For a copy of the guidelines contact your state survey agency.

ICF-MR programs from serving older persons in a manner that the operator deems appropriate to meet the needs of older persons.

The 1988 ICF-MR regulations and interpretative guidelines reflect a lifespan perspective and recognize that general programming focus and content may vary for older residents. The 1988 regulatory definition of *active treatment* takes into account the aging process and reality that some skills may decline with consideration of the "prevention or deceleration of regression or loss of current optimal functional status" (Reference: 483.440).[4] Other guidelines provide further information for programs serving older persons (see box on page 38).

These standards and guidelines offer operators more flexibility in designing and operating senior services within the ICF-MR program. These guidelines have a lifespan focus, permit a wide range of age-related programming, and call for novel and creative means of providing choice related activities and services within the context of a senior program.

☐ ***Identifying information/communication barriers***

- □ *look at the types of complaints about site survey results and inspections offered by Medicaid providers serving older persons -- does there seem to be a pattern emphasizing a lack of understanding of aging and aging programs on the part of the surveyors?*
- □ *look at how records are exchanged and information conveyed -- is there a problem in sharing needed information?*
- □ *look at state policies on delivering services to seniors -- are they consistent? do they hinder understanding?*
- □ *look at the type of information that is available (or made available) to providers about aging and senior service options.*

Financial barriers

Fragmented funding sources are often cited as significant obstacles to integration. For example, aging service programs and mental retardation/ developmental disabilities programs are funded by different government sources and are operated independently. While aging service programs are primarily funded by Older Americans Act and state/local funds, mental retardation and developmental disabilities services are heavily reliant on federal Medicaid dollars as well as state and local tax revenue.

Competition for limited financial resources and the tendency to preserve traditional spheres of responsibility account for some reluctance on the part of both the aging and developmental disabilities networks to extend services to the emerging older population of persons with developmental disabilities. These agencies, like all human services agencies, are being pressured to provide more services and programs with fewer real dollars. Program overloads and shortage of funds, coupled with a lack of fiscal incentives to support special initiatives, accounts for some of the absence of the necessary and desirable linkages that could expand participation of elderly individuals with developmental disabilities within aging network sponsored programs and services.

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[4] The "References" refer to citations from the regulations governing this program, that is, 42 CRF 483, Subpart D (see *Federal Register*, June 3, 1988). The "W" numbers are "tag numbers" associated with standards for specific regulatory citations identified in the Interpretative Guidelines.

Another barrier relates to regulatory and/or compliance standards required by the developmental disabilities system for reimbursement. While the aging network is not barred from serving older persons with a developmental disability, the developmental disabilities system often will not reimburse aging network programs because the aging programs lack certification.

☐ ***Identifying financial barriers***

- ☐ *look at the state standards that are in effect -- do they provide reimbursements based upon diagnoses rather than equalizing reimbursement based upon functional needs levels?*
- ☐ *look at what monies are used to underwrite/fund senior programs -- are they available in reasonably sufficient amounts?*
- ☐ *look at regulatory barriers to serving older persons with developmental disabilities.*
- ☐ *look at how the state/region fosters the flow of funds -- are they awarded on a competitive basis or are they distributed equitably? do providers vie for funds or are they targeted?*

Coordinative/administrative barriers

Lack of coordination is a major barrier to integration. Often this is due to the large number of Federal agencies involved in funding and regulating services affecting elderly persons and individuals with developmental disabilities. Major federal agencies involved include:

- Social Security Administration
- Department of Health and Human Services
- Health Care Financing Administration
- Public Health Service
- Employment and Training Administration (US Department of Labor)
- Rehabilitation Services Administration (US Department of Education)

Each of these federal agencies has its own operational policies, and frequently does not regard the impact of its policies on other federal, state and local efforts. This results in service definitions, eligibility requirements, terminology, report forms, and record keeping demands that differ for each program and system. Of particular concern are the inconsistences of the Medicaid program requirements that are based upon health program models, and the desire of disability providers to provide "normalizing" experiences and activities. These types of conflicting or competing situations are often also found at the state or local level.

Other cited deterrents to coordination are:

- the lack of formal linkages between the aging and developmental disabilities networks at the state and local level;
- the lack of clear delineation of network responsibilities;
- a lack of cooperative and coordinated advocacy efforts; and
- the lack of funding for case management and other means to encourage coordination.

☐ ***Identifying coordinative and administrative barriers***

- *look at how federal policies are interpreted within the state -- is there an effort to coordinate discrepant policies? do these policies reflect particular local conditions and needs?*
- *look at how state units on aging and the disability agencies interpret their responsibilities and relate to their constituent groups with regard to aging and developmental disabilities.*
- *look for formal linkages, such as interagency agreements and memoranda of understanding.*
- *look at who speaks to whom - which agencies have interagency agreements or participate on policy coordinating committees.*
- *look at the Medicaid reporting rules -- does the state Medicaid agency apply them with reason? does the application cause problems for aging services providers?*
- *look for evidence of advocacy at the state and local level.*

Programmatic barriers

The differences between programs based on the interdisciplinary-professional team (in the developmental disabilities agencies) and social (in aging network agencies) models represents another obstacle. Social services programs, such as those funded under the Older Americans Act and other federal social program grants have staffing and program standards that differ from those of health-related and habilitation programs funded under Medicaid or state funds. Thus, there is a question of the compatibility of aging programs with the existing funding streams for older persons with a developmental disability. There are also a number of questions that have arisen from program concerns (see box on page 42).

The requirements and restrictions of the many state consent decree or judgments may also impede integration. The mandates for active treatment and goal-based programming, negotiated in an era when few if any senior program alternatives were present, may now be seen as insensitive to the needs of some older individuals who may necessarily be more "retired" than fully active.

There is often a lack of staff in the aging network who are trained and experienced in providing supervised care to older persons with a developmental disability. Integrating this population into aging network programs may create significant demands on staff and require changes in patterns of services that are beyond current staff capabilities.

The lack of full-time structured activities at senior citizen centers may be an additional problem for some older persons with a developmental disability since they may have difficulty dealing with unstructured time given a lifetime of sheltered care.

The absence of adequate transportation is often the most significant barrier in providing services to older persons with a developmental disability. The architectural design of some aging service sites may make them inaccessible to older persons with mobility limitations. With the passage of the Americans with Disabilities Act of 1990, this will become less of a problem over time.

PROGRAM QUESTIONS

- *What is the best ratio of older persons with a developmental disability to elderly persons in a senior program environment in order to maintain the character of an aging network program?*
- *If there are additional requirements for programming for elderly persons with developmental disabilities within adult day care, will these requirements disrupt the current programming or can they be used to enhance it?*
- *What effect does the inclusion of older persons with a developmental disability have on the attendance of other older persons at nutrition sites, senior citizens centers and adult day care programs?*
- *What kind of process is most effective in planning the implementation of such integration?*
- *What are the responsibilities of the aging network and the developmental disabilities system to make integration work?*

Questions are also raised as to the implications of the develop-mental disabilities relevant provisions of the Nursing Home Reform Act of 1987 which call for a pre-admission screening of all nursing facility referrals who are suspected of being mentally retarded or having a developmental disability and the subsequent annual review of all nursing home residents with mental retardation and developmental disabilities. These reviews are known as the PASARR process (for Preadmission Screening and Annual Resident Review). They have left many states in the situation of having to provide for a new programmatic scheme of specialized services within the context of nursing home operations as well as having to develop an immediate range of living alternatives in the community. Programmatic barriers related to the overlay of a developmental disabilities system on the nursing facility operations may lead to new problems.[5]

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[5] Readers are urged to contact the state PASARR coordinator for more information on what is being done in your state to comply with the mental retardation and developmental disabilities provisions of the Nursing Home Reform Act. To obtain the name of your State coordinator contact your state mental retardation/developmental disabilities authority or contact the National Association of State Mental Retardation Program Directors (113 Oronoco Street, Alexandria, VA 22314; telephone 703/683-4202).

☐ *Identifying programmatic barriers*

- ◻ *look to see if there are initiatives or programs to provide bridges to retirement? do agencies undertake training to teach use of unstructured time?*
- ◻ *look at how agencies in the aging network and in the developmental disabilities system share program ideas and methods. are there staff exchanges or joint training opportunities?*
- ◻ *look at what methods are undertaken to educate personnel of nursing facilities related to the state's operations under the Nursing Home Reform Act of 1987. has programmatic instruction taken place? are technical materials and resources available?*
- ◻ *look at how court related decrees and judgments are interpreted. do they permit leeway for retirement and movement into senior programs of the persons choice?*
- ◻ *look at what types of programs are offered to seniors. do they look age-appropriate? do the seniors involve themselves in activities that other, non-disabled seniors would do? are the programs open to anyone with similar needs?*

Education and training barriers

One of the critical deficits identified as a major barrier to integration is the lack of adequately trained professionals. Persons who are knowledgeable about both aging and developmental disabilities and who understand how to meet the programmatic and life support needs of older persons with a developmental disability are not found in significant numbers in either service system.

Other education and training related barriers include:

- lack of adequate agency staff and funding to permit staff participation in cross-network training activities;
- resistance by professionals to the development of aging and developmental disabilities as a sub-specialty;
- the lack of focus at higher educational institutions, such as university-based gerontological centers and special education departments, to train professionals to be knowledgeable in both developmental disabilities and aging;
- lack of geriatricians and other specialized physicians who focus on older persons with a developmental disability; and
- lack of knowledge of existing education and training resources regarding developmental disabilities and aging by members of both networks.

With the passage of the 1987 amendments to the Developmental

Disabilities Assistance and Bill of Rights Act, the Administration on Developmental Disabilities has been able to support a number of university affiliated programs in developmental disabilities in developing training centers in aging and developmental disabilities. These centers are listed on page 99.

☐ ***Identifying education and training barriers***

- ☐ *look if any formal training programs exist that are open to staff of both the aging network and the developmental disabilities system.*
- ☐ *look if there are courses, training materials, and videos available for agencies.*
- ☐ *look if cross-training is the norm or are staff persons of each network trained in their own agencies.*
- ☐ *look if the college/university based aging or gerontology centers provide courses, seminars and workshops on disability and aging.*
- ☐ *look if the university affiliated program in developmental disabilities in the state has taken the initiative to offer training in the area of older adults/aging.*
- ☐ *look if the state developmental disabilities council help support conferences and workshops in aging.*
- ☐ *look if the curricula of state medical schools or physician continuing education programs contain segments/modules on aging and lifelong disability.*
- ☐ *look if the state gerontological association have an annual conference at which lifelong disability is a topic.*
- ☐ *look if staff members of programs for seniors (residential and day) at disability agencies received any special training addressing aging.*
- ☐ *look at the quantity and type of funds that are available to support cross-training in aging and developmental disabilities.*

Commentary

Despite existing barriers, many local aging and developmental disabilities agencies are involved in different stages of exploring the integration possibilities and processes. While some have yet "to get involved," others have had both positive and negative experiences with integration over the past few years. From our experiences, we offer the following:

- a elemental barrier to integration is the lack of clear policy in defining the roles and responsibilities among state and local agencies which address the needs of this population of elders.
- many barriers are attitudinal; some arise from the nature of the organizations and agencies involved, others from the financial constraints under which many aging network and developmental disabilities agencies function.
- other barriers are related to problems of communication within

and between agencies, the manner and method of financing services and the paucity of appropriations available for them, the lack of definitions for program appropriateness and inadequate or inappropriate regulatory boundaries, and the lack of staff with sufficient training or experience with older individuals with handicapping conditions. □

Section 5

Overcoming Barriers to Integration

To aid state efforts to promote an aging agenda, we have prepared a section that offers a series of possible strategies that could be undertaken to address the barriers identified in the previous section.

☐ ***Possible strategies to address policy barriers***

To overcome barriers related to the lack of public policy relative to the state's aging and elderly population of seniors with a developmental disability:

- *the state disabilities agency and state unit on aging could develop a policy identifying older individuals with a developmental disability as a special population requiring special emphasis in the definition and provision of program services.*
- *the state disabilities agency and state unit on aging could establish by regulation the rights of older persons with a developmental disability to receive the same options for services which the general older population receives in accessing generic services.*
- *the state disabilities agency and state unit on aging could ensure that regulations promote, where possible, individual choice in determining life patterns, rather than reinforcing system imposed patterns of behavior and routine.*

To overcome barriers related to understanding the population of individuals with a developmental disability and in planning coordination of all levels of services provision:

- *the state disabilities agency and state unit on aging could enter into joint agreement to share planning information and to coordinate planning efforts at both state and regional/local levels.*
- *the state developmental disabilities council could ensure that at least several members of the council arerepresentatives of state or area agency on aging advisory councils.*

Possible strategies to address attitudinal barriers

To overcome barriers related to the public's awareness and understanding of the older population of persons with a developmental disability and the needs of older individuals with a developmental disability:

- *the state disabilities agency, state unit on aging and state developmental disabilities council could develop a major public education campaign to combat prejudice toward elderly persons with developmental disabilities and to improve the image of the aging experience in the eyes of the general public, the media, senior service providers and elderly persons with a developmental disability themselves.*
- *the state disabilities agency and state unit on aging could provide community education for care providers, parents, consumers and their families, advocates, legal professionals, community service groups and boards, legislators, and private medical practitioners to encourage the integration of older persons with a developmental disability.*

To overcome barriers related to the lack of understanding of older persons with a developmental disability by other non-disabled elders:

- *the state disabilities agency and state unit on aging could develop a videotape that would be designed to educate the general public and staff of the two networks in order to destigmatize aging, negate prevalent adverse stereotypes of seniors with developmental disabilities, and to demonstrate successful integration strategies.*
- *the state disabilities agency and state unit on aging could educate the elderly about the "normalization" process, emphasizing the similarity of needs of all elderly persons, regardless of disability status.*

To overcome barriers related to the lack of training and experience of staff working in both the aging network and the developmental disabilities system about the subject of aging and developmental disabilities:

- *the state disabilities agency and state unit on aging could collaborate in providing cross-education and training sessions for staff in both the aging and developmental disabilities service agencies to increase their awareness and understanding of the issues relative to the aging of older persons with a developmental disability.*
- *the state disabilities agency and state unit on aging could collaborate in providing cross-education and training for staff in both the aging and*

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developmental disabilities service agencies to increase their sensitivity and flexibility in meeting the needs of older persons with a developmental disability.

- *the state unit on aging and state disabilities agency could develop and show to developmental disabilities providers films about aging related activities, such as adult day care and senior centers which emphasize the similarities between seniors with a developmental disability and those without a disability.*
- *the state unit on aging and state disabilities agency could conduct "Handicapism Awareness Sessions" within senior centers, nutrition sites, and adult day care programs to let staff and consumers air their fears, frustrations and feelings.*

To overcome barriers related to the lack of knowledge of the needs of families with an older adult with a developmental disability:

- *the state disabilities agency and state unit on aging could identify the needs of the families of older persons with a developmental disability and communicate this information to all service providers.*

To overcome barriers related to the lack of exposure to older adults with a developmental disability:

- *the state disabilities agency and state unit on aging could develop means by which older individuals with a developmental disability are exposed to age-appropriate activities and given choices of generic services thus enabling staff and administrators to become familiar with them.*
- *the state disabilities agency and state unit on aging could develop means by which older individuals with a developmental disability and their advocates can understand available opportunities.*
- *the state disabilities agency and state unit on aging could encourage aging network program staff to become familiar with their clientele with a developmental disability.*

☐ *Possible strategies to address information and communication barriers*

To overcome barriers related to the lack knowledge about the population of older/elderly persons with a developmental disability:

- *the state disabilities agency and state unit on aging could collaborate on, or encourage an university center to carry out, a project to collect and analyze contemporary information about older persons with developmental disabilities, their needs, and the services they have and need to utilize.*
- *the state disabilities agency could review data from appropriate sources to identify characteristics and needs of older persons with a developmental disability.*

To overcome barriers related to the lack of knowledge of each locality's population of older/elderly persons with a developmental disability who are living with their families or who are in need of special services:

- *the state disabilities agency could review the available data files and develop a local registry of elderly persons with a developmental disability, conduct outreach within localities to add to that registry, and coordinate these activities with the local social services agencies.*
- *the state disabilities agency could enhance existing information and referral services that provide information on eligibility criteria and specific services available to older persons with a developmental disability and their families.*
- *the state disabilities agency and state unit on aging could develop a resource guidebook for local service providers and families of older persons with a developmental disability consisting of available services, regulations, guidelines for accessing services, advocacy services, information and referral, and residential and legal services.*
- *the state unit on aging and state disabilities agency could develop a specialized case finding and case management program which would include home visits and "one-stop-shop" counseling and referral to insure linkage with appropriate services.*

To overcome barriers related to the lack of coordination among the various agencies concerned with services to elderly or handicapped persons:

- *the state unit on aging and state disabilities agency could develop an interagency communication system to share information and address specific program concerns.*
- *the state unit on aging and state disabilities agency could coordinate and disseminate information regarding program requirements and regulations to local aging services providers.*

☐ *Possible strategies to address financial barriers*

To overcome barriers related to the financial aspects of providing services:

- *the state disabilities agency could modify existing regulations to broaden the range of core services potentially made available within its regulated programs for older individuals with a developmental disability and could allow for the use of non-certified, age-appropriate activities to meet the program/services needs of older individuals with a developmental disability.*
- *the state disabilities agency could expand "day initiatives" funds to allow for the placement of elderly persons with a developmental disability into more appropriate programs.*
- *the state disabilities agency could re-examine payment scales and reimbursement linked to "individual need" in all program funding mechanisms and determine whether funds could be more effectively allocated.*

- *the state disabilities agency could use the budget process to request financial incentives and federal supports topromote greater access by older persons with a developmental disability to more appropriate services and could explore funding options for localities to provide additional services to older persons with a developmental disability where gaps in generic services exist.*
- *the state unit on aging and state disabilities agency could publish and disseminate information regarding alternative sources of funds and procedures to obtain additional developmental disabilities services funds.*

☐ *Possible strategies to address coordination and administrative barriers*

To overcome barriers related to the administrative aspects of state agency efforts:

- *the disabilities agency could develop a joint Memorandum of Understanding (MoU) to encompass the following:*
    - *encourage the staff of each agency to share expertise, creatively solve common problems, and advocate for services;*
    - *plan and implement appropriate models or demonstration programs;*
    - *exchange information and data;*
    - *use cooperative funding opportunities available from federal agencies and private organizations;*
    - *plan jointly for future needs;*
    - *identify current gaps in services;*
    - *develop joint annual workplans;*
    - *consult on development of state plans;*
    - *encourage cooperation and coordination of services between local aging and developmental disabilities agencies;*
    - *coordinate public education and awareness campaigns;*
    - *develop guidelines for aging program requirements and regulations;*
    - *develop guidelines for pre-service and in-service training and education program in aging (gerontology and geriatrics) with application to disabilities;*
    - *adopt an agreed-upon, standardized system of data gathering and bookkeeping; and*
    - *make joint recommendations for legislative action.*
- *the state unit on aging and state disabilities agency could designate a focal point at the state level to ensure that the needs of older persons with a developmental disability will be met through careful assessment, coordination, and planning of statewide services.*
- *the state unit on aging and state disabilities agency could provide each local developmental disabilities agency and area agency on aging (AAA) with technical assistance to strengthen their capacity to coordinate, plan and deliver services to older persons with a developmental disability.*
- *the state unit on aging and state disabilities agency could enhance theopportunities for local agencies to form linkages, coalitions, and other cooperative relationships in order to become advocates for older persons with a developmental disability.*

☐ *Possible strategies to address programmatic barriers*

To overcome barriers related to program inadequacies:

- *the state disabilities agency could provide ongoing technical assistance and inservice training to local aging services providers to ensure compliance with the provisions of the state's laws and the agency's rules and regulations.*

- *the state disabilities agency could review its regulations and requirements related to the Medicaid programs in order to allow and encourage "supportive retirement" as a lifestyle option for older persons with a developmental disability by broadening the applicability of the definition of "active treatment," specifically by:*

  - *allowing goal-based programming to address degenerative conditions, and*

  - *facilitating training in the productive use of leisure time and sustenance of current skills.*

- *the state disabilities agency could further develop policies and refine promoting the rights of older persons with a developmental disability.*

- *the state disabilities agency could develop "retirement" program options for older persons with a developmental disability who are currently in sheltered workshops to provide an emphasis on age-appropriate leisure and socialization activities.*

- *the state disabilities agency could communicate to its field agencies that the agency's regulations no longer require set hours of program per day, but a weekly program minimum as part of the "active treatment" requirements.*

To overcome barriers related to both transportation and architectural aspects of aging and developmental disabilities programs:

- *the state disabilities agency could encourage its network of agencies to provide programming in reasonable proximity to an older individual's place of residence to avoid the problems inherent with long-distance commuting.*

- *the state disabilities agency could encourage the use of volunteer transporters and agencies to share resources to provide transportation (such as agency vans, drivers, and maintenance).*

- *the state disabilities agency and state unit on aging could educate professionals who are responsible for transportation systems about the special needs of older persons with a developmental disability.*

- *the state disabilities agency and state unit on aging could revise the physical program environments to meet the special spectrum of needs of older persons with a developmental disability.*

- *the state unit on aging and statedisabilities agency could provide technical assistance to community residences about the necessary modification that will make the homes more appropriate for older persons with a developmental disability as they "age in place" in their residence.*

To overcome barriers related to the inadequacies of supports to various programs offering services to older persons with a developmental disability:

- *the state disabilities agency could involve more gerontologists, geriatricians, and aging network staff in developing appropriate programs for older persons with a developmental disability who reside in a developmental center.*
- *the state unit on aging and state disabilities agency could ensure the development of collateral systems to existing aging services which enhance the program supports that will meet the needs of older persons with a developmental disability by*
  - *establishing senior peer programs to foster integration, and*
  - *establishing incentives for community senior citizens programs to involve older persons with a developmental disability in their programs.*
- *the state unit on aging and state disabilities agency could explore means by which elderly parents as well as their older but under 60-year-old adult dependent(s) with a developmental disability could routinely use nutrition sites and other aging network services.*

☐ *Possible strategies to address education/ training barriers*

To overcome barriers related to the education and training of personnel who work in both the aging network's programs and in the developmental disabilities programs, as well as those who work in other systems who come in contact with older persons with a developmental disability:

- *the state disabilities agency could develop and implement a comprehensive training needs assessment to determine staff development needs.*
- *the state disabilities agency could develop a statewide in-service training system to meet the needs of staff in particular disciplines, as well as provide for interdisciplinary training, to individuals working with older persons with a developmental disability.*
- *the state disabilities agency could develop and implement a pre-service and in-service curriculum for training all staff who work with older persons with a developmental disability.*
- *the state unit on aging and state disabilities agency could fund and otherwise support workshops and seminars on how to best provide services to older persons with a developmental disability.*
- *the state disabilities agency could contract with specialists in the area of gerontology and geriatrics to aid in the development of special training programs on aging and aging services.*
- *the state unit on aging and state disabilities agency could develop agreements with medical schools and allied health services program to train students in treating older persons with a developmental disability.*
- *the state unit on aging and state disabilities agency could stimulate appropriate training for medical students, and for the expansion of degree program internships and traineeships to better prepare health care professionals to meet the needs of older persons who have a developmental disability.* ☐

Section 6

Developing Plans

In this section, we discuss both the formal and informal planning processes that can be undertaken by states and localities, how to approach planning and needs assessments, and organizing planning and development efforts. You will find information on the requirements under the relevant federal statutes for state developmental disabilities and aging plans; the second section explores some conceptual issues; the third section offers a guide to developing plans specifically targeting a locality's or state's older population of persons with developmental disabilities; and the fourth section offers some guidance on data collection.

Federal requirements for state plans

Currently, two federal statutory requirements call for states to produce plans related to developmental disabilities and aging. They are the:

- Developmental Disabilities Assistance and Bill of Rights Act, and the
- Older Americans Act

Requirements for developmental state disabilities plans

Title I, Part B, §121 of the Developmental Disabilities Assistance and Bill of Rights Act requires each state, every three years, to develop a state developmental disabilities plan. The state plan is then to be reviewed annually for relevance and updated or revised as needed. The state plan is required to:

- describe the extent and scope of services, supports and other assistance being provided, or to be provided, to persons with developmental disabilities under other State plans for federally assisted programs, including aging;
- provide an analysis of the special and common needs of all subpopulations of persons with developmental disabilities, including those who are elderly; and
- formulate objectives with regard to policy and service demonstrations to address the issues related to all subpopulations of persons with developmental disabilities which may be identified by the state planning council.

☐ Developing developmental disabilities state plans

When developing state plans to serve persons with developmental disabilities, it is important to target older individuals by identifying such persons in the narrative with analyses, objectives, and activities.[1] [2]

Consider:

- *including age categories in state population estimates of individuals with developmental disabilities that coincide with age categories used in the state unit on aging's state plan (minimally using the category 60+; preferably, 60+ and 75+; other corresponding ranges or intervals may also be used -- check with your state unit on aging for the categories in use within the state).*
- *identifying current activities being undertaken by state mental retardation/ developmental disabilities, aging, social services and health agencies to address this population.*
- *identifying state-specific conditions that either facilitate or inhibit the provision of activities/services/programs to this population.*
- *targeting specific initiatives that will be undertaken to aid the state in addressing this population, including*

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[1] A good source for day program information, particularly adult day care, is *Standards and Guidelines for Adult Day Care*, available from the National Council on the Aging, 409 Third Street, S.W., Washington, DC 20024; 202/479-1200. For national survey information on the use of adult day care by persons with developmental disabilities see *The National Adult Day Center Census - 89: A Descriptive Report*, available from the Institute for Health & Aging, School of Nursing, University of California-San Francisco, San Francisco, CA 94143.

[2] Consider health promotion goals for seniors consistent with those recommended by the Institute of Medicine. We would recommend using the following report as a reference: *The Second Fifty Years: Promoting Health and Preventing Disability*, available from National Academy Press, 2101 Constitution Avenue, N.W., Washington, DC 20418; telephone 202/334-3313 or 800/624-6242.

- *underwriting efforts to develop population estimates or needs assessments;*
- *underwriting investigatory studies or planning efforts to help define policy and programmatic initiatives;*
- *underwriting demonstration projects to promote community integration of seniors with developmental disabilities into aging network programs;*
- *underwriting conferences, workshops, and training programs to help cross-train staff in agencies serving older persons with developmental disabilities about issues specific to older persons with developmental disabilities;*

☐ *facilitating efforts to produce interagency agreements between the mental retardation/developmental disabilities agency and the state unit on aging; and promoting other efforts as deemed needed or necessary by the Council.*

☐ *targeting specifically needs of older persons and the means of addressing their needs in the areas of residential, family support, day program, and health maintenance and prevention services.*

Requirements for state unit on aging plans

Title III, Part A, §307 of the Older Americans Act requires each state unit on aging to develop a state plan for a two, three, or four year period. The state plan requirements, as they relate to developmental disabilities, are to:

- coordinate ombudsman services with the protection and advocacy systems for individuals with developmental disabilities as established under part A of the Developmental Disabilities Assistance and Bill of Rights Act;

- make nutrition services available to individuals with handicaps or disabilities who, although not age 60 or older, reside in housing facilities occupied primarily by elderly persons at which congregate nutrition services are provided and to individuals with disabilities who reside at home with and accompany older individuals who are otherwise eligible under the Act; and

- provide, for the needs of older individuals with severe disabilities, assurances that the state unit on aging will coordinate planning, identification, assessment of needs, and services for older individuals with disabilities with state agencies which have primary responsibility for individuals with disabilities, including severe disabilities, and develop collaborative programs, where appropriate, to meet the needs of older individuals with disabilities.

Requirements for area agency on aging plans

Title III, Part A, §306 of the Older Americans Act requires each area agency on aging to develop an area plan for a two, three, or four year period. The area plan requirements, as they relate to developmental disabilities, are to:

- assure that the use of outreach methods will identify individuals eligible for assistance under the Act, including older individuals with developmental disabilities;
- include in their planning base and projections for service the needs of older individuals with the "greatest social need," which includes older persons with developmental disabilities.

☐ *Developing state unit on aging plans and area agency on aging plans*

In developing state or area plans for a state's or area's aging population, it is important to target analyses, objectives, and activities to address the needs of older individuals with developmental disabilities.

Consider:

- ☐ *providing population estimates of older persons with developmental disabilities.*
- ☐ *identifying current activities being undertaken by state developmental disabilities and aging agencies to address the needs of this population.*
- ☐ *identifying state-specific conditions that either facilitate or inhibit the provision of activities/services/ programs to this population.*
- ☐ *targeting specific initiatives that will be undertaken to aid the state in addressing this population, including*
  - *specifying efforts to be undertaken within aging network programs to address the needs of this population;*
  - *promoting the development of interagency agreements between the area agencies on aging and local developmental disabilities agencies.*

Conceptual issues

A number of conceptual issues affect the planning of services for older persons with developmental disabilities. These include:

- system differences
- population diversity
- increased longevity
- two-generation elderly families
- aging in place
- transitions and transfers
- retirement concerns

System differences

The aging of individuals with a developmental disability poses special challenges to both the aging network and the developmental disabilities system. Historically, the systems serving persons who are elderly or those with developmental disabilities have been separate and independent.[3] The developmental disabilities system has historically not dealt with large numbers of clientele who have reached old age; it tended to emphasize younger and work age adults. The aging network has had little experience with atypical seniors. It has generally concentrated on the wide range of needs of the older population. The differences between aging and developmental disabilities network services tend to be characterized by:

- the lack of case orientation (as opposed to the disability system where case managers are an important ingredient),
- consumer freedom to come and go (as opposed to the disability system where intake and discharge form a "gatekeeper" function),
- assessment based upon functional needs (as opposed to the disability system where diagnostic and clinical descriptors are often the basis for service eligibility), and
- sustenance of functional abilities and socialization opportunities (as opposed to the disability system where there is a continual emphasis on new learning and training).

Addressing the needs of a growing number of older persons with developmental disabilities, therefore, requires creative and collaborative efforts in developing plans.

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[3] The *aging network* is defined as the system of federal, state and local agencies, organizations and institutions which are responsible for serving and/or representing the needs of older people. The network, according to *An Orientation to the Older Americans Act* (see page 28), is variously involved in service systems development, advocacy, planning, research, coordination, policy development, training and education, administration and direct service provision. The elements of the network include the Administration on Aging (AoA), 57 State Units on Aging (SUAs), some 664 Area Agencies on Aging (AAAs), a number of university based centers on aging, and numerous local service provider agencies. Because of the nature of Older Americans Act funding, the linkage among these elements runs throughout the network. Older American Act funds are appropriated to the states via the AoA. The SUAs then distributed them to the AAAs, who in turn contract with local providers. The AAAs, however, are autonomous entities within the states and are not under the line authority of the SUAs (their plans and budgets, however, are subject to review by the SUA). In contrast, the developmental disabilities system is a much looser network, composed of a federal agency as well as state disability, education, health and social services entities. At the federal level, the Administration on Developmental Disabilities is the federal agency that administers the three elements enabled under the Developmental Disabilities Assistance and Bill of Rights Act: the developmental disabilities planning councils, the university affiliated programs in developmental disabilities (UAPs), and the protection and advocacy agencies (P&As). At the state level, the system can include programs for children with handicapping conditions, special health and prevention services, vocational rehabilitation and independent living centers, and the state mental retardation and developmental disabilities agencies (which in most instances are the primary agencies concerned with older persons with developmental disabilities). However, the linkages among these elements can be very tenuous; in most instances, each element is independent of the others. Federal funding under the Developmental Disabilities Assistance and Bill of Rights Act goes only to the planning councils, the UAPs, and the P&As. State and local developmental disabilities services are funded under state and local appropriations and the agencies have no formal relationship to the federal and state entities defined in the Developmental Disabilities Assistance and Bill of Rights Act. The primary source of federal dollars for state/local services is the Medicaid program; with regard to educational services, some support from come special federal children's programs to the state and local educational agencies. Federal vocational rehabilitation and independent living aid is also funneled to the states via the state vocational rehabilitation agencies.

☐ ***Plan considerations***

- ☐ *Has the document taken into account cross-planning that would bridge the two systems?*
- ☐ *Does the planning document consider differences in terminology and service practices?*

Diversity within the older population

Individuals with developmental disabilities represent a population with varying levels of functional impairments, Thus, they may need services from various facets of the aging and disability service systems. Program planners need to consider each of these varying levels of need when planning for services (see also Section 9). The service needs can be viewed as fitting three broad characterizations:

- The first grouping is made up of older individuals with mild impairments who have been fairly independent all their adult lives and who because of age-associated impairments will need special assistance from social, health or aging services. These persons, whose level of impairment falls generally within the definition of *"disability"* under the Older Americans Act, are most like other seniors in need of these types of social services.[4] Estimates are that individuals within this group make up the bulk of the older population of persons with developmental disabilities, but represent only a minority of known older individuals with developmental disabilities.

- The second grouping is made up of older individuals with severe impairments. In many instances, these seniors, whose level of impairment falls generally within the definition of *"severe disability"* under the Older Americans Act, are like other seniors who would benefit from targeted senior services, adult day care and other specialized retirement programs. These persons present the greatest challenge to coordination between the aging and developmental disabilities services networks. Estimates are that the individuals in this group may make up the largest segment of known older persons with developmental disabilities.

- The third grouping is made up of older individuals with lifelong disabilities who now have age-associated impairments, and who as they age, might be characterized as "frail" and may require specialized supportive or long term services. These are the persons whose physical and mental functions are severely limited. Often they make up the residual populations of public residential facilities or may be residing in nursing facilities. However, they are also more increasingly seen in specialized community developmental disabilities or health care programs. Estimates are that this group is a small, albeit mostly known group among older persons with developmental disabilities.

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[4] See page 18 for the Older Americans Act definitions of "disability" and "severe disability" and pages 20 and 61 for definitions of "frailty."

☐ ***Plan considerations***

- ☐ *Has the planning body made an effort to collect demographic information?*
- ☐ *Does the planning document take into consideration the heterogeneity of the population of older persons with developmental disabilities?*
- ☐ *Is the planning based on reasonable population estimates for the current and future population?*
- ☐ *Are special considerations given to linking needs of diverse groups to service development projections?*

Implications of increased longevity

People in the general population are surviving longer. People with disabilities are also surviving longer because of better health care, better social conditions, and better housing. Increased longevity has created a demand for services and special attention that many states are ill-prepared to address. Since many states had developed child-oriented developmental and remedial educational services, and adult-oriented vocational and social developmental services, the new demand for senior-oriented developmental disabilities services was unanticipated. Further, there is still disagreement among developmental disabilities policy makers and administrators as to whether to create a parallel senior services track within developmental disabilities services or to collaborate with the aging network in the use of existing or augmented senior services within that network.

Two examples of the "new" problems arising from increased longevity focus on Down syndrome and Alzheimer's disease. Persons with Down syndrome, a condition associated with mental retardation, are now also experiencing longer life. In the 1930s, the life expectancy of a person with Down syndrome was about 15-20 years; now life expectancy is at least or beyond age 50. With longer life there is precocious or premature aging. People with Down syndrome, for example, who are in their 40s and early 50s have the physical appearance and condition of seniors who are in their 70s and 80s. They also have a shorter lifespan; very few survivors are found in their 60s.

The second example concerns the incidence of Alzheimer's disease, which is higher among persons who have Down syndrome than in older persons in the general population.[5] One out of every three persons with Down syndrome can be expected to eventually have the physical signs of

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[5] For a review of the research related to Alzheimer's disease and Down syndrome see *Aging and Developmental Disabilities: Challenges for the 1990s*, the proceedings of the Boston Roundtable on Research Issues and Applications in Aging and Developmental Disabilities, available from the Special Interest Group on Aging, c/o American Association on Mental Retardation, 1719 Kalorama Road, N.W., Washington, DC 20009.

Alzheimer's disease. Upon autopsy most persons with Down syndrome show the brain pathology typical of Alzheimer's disease. These "new" problems will require more attention to the application of clinical diagnostics among older persons with Down syndrome to look for early signs of Alzheimer's; more training of line staff to be effective observers and interventionists; and planning for senior services for a group of individuals whose chronological age does not yet entitle them to receive such services.

☐ ***Plan considerations***

- ☐ *Does the plan consider the problems associated with an increase in the prevalence of Alzheimer disease among persons with Down syndrome?*
- ☐ *Does the plan consider the impact of changes in longevity and the special problems posed by premature aging?*

Special needs of two-generation elderly families

In the general population, it is primarily the family that provides most "services" for elderly persons. Because of the efforts of family members, as many as 60% of extremely impaired elderly live outside of institutions and fully 80% of their service needs are met by an informal support network. In most cases, such supports are provided by a spouse or by adult daughters, daughters-in-law, or sons. Unlike most elderly persons, older persons with developmental disabilities generally do not have children or a spouse on whom they can depend for support. In some cases, they live with very old parents who still provide their day-to-day supports. In other instances, it is siblings or the children of siblings who provide care. A small proportion of individuals with a developmental disability who receive state-supported services continue to live with their families into old age. Although the numbers of elderly persons with developmental disabilities who live with their families is estimated to be modest, future trends indicate that this number will increase markedly.

The two-generation elderly family, where the parents are in their 70s or 80s and a son or daughter with a developmental disability may be in his/her 50s and 60s, presents a planning challenge since each may need specific aging services to help meet some of their needs.[6] Many of these older sons or daughters may not be known to service providers as they have remained at home and may have not been involved with any human services agencies. It is an all too common situation to be alerted to the existence of these individuals only after their parent has been hospitalized or has died. Service planning concerns with such families include issues of guardianship[7], permanency planning, accepting or finding alternative housing, and the need to address the psychological reactions to death of parents or separation from family.

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[6] See *Parents of the Adult Developmentally Disabled*, by Meg Gold; available from the Hunter-Brookdale Center on Aging, 425 East 25th Street, New York, NY 10010-2590. For a summary of the research in the area of families, see *Aging and Developmental Disabilities: Challenges for the 1990s*, the proceedings of the Boston Roundtable on Research Issues and Applications in Aging and Developmental Disabilities, available from Special Interest Group in Aging, c/o American Association on Mental Retardation, 1719 Kalorama Road, N.W., Washington, DC 20009. For additional information on outcomes of studies with families of older persons with a developmental disability, contact Dr. Marsha M. Seltzer, University of Wisconsin, Waisman Center, 1500 Highland Avenue, Madison, WI 53705.

The problems faced by parents who continue to bear the burden of care for an older adult son or daughter with a developmental disability poses a difficult choice for planners. Many states have yet to link generally available aging services with more traditional developmental disabilities services in such situations or be sufficiently robust in their service offerings to address this special situation. A good example of partnership arrangements is a disability agency attending to an aging son or daughter with a disability and an aging agency attending to the parent's aging related needs, such as in-home and other related services.

☐ ***Plan considerations***

- *Have guardianship, protective services, and other forms of family assistance been considered in the planning document?*
- *Has special thought been given to planning for the needs of older families?*

Aging in place

"Aging in place" means growing older while remaining in the same residential setting. Generally this notion refers to the problem of increasing frailty of older individuals already living in a community setting and the changing demands that frailty makes upon the staff and the environment. Many older persons with mental retardation residing in group homes, apartments, and similar settings, or with their families have aged and their abilities and needs have changed.

Some older persons are experiencing medical complications or frailty that accompany the normal aging process.[8] Such frailty has been defined in the Older Americans Act as having a physical or mental disability that restricts the ability of an individual to perform normal daily tasks and which threatens the capacity of an individual to continue to live in the community setting. This growing frailty may necessitate admission to a long-term care setting; however, in many instances such an action can be precluded by some simple activities; for example, buildings can be adapted or changed to compensate for the older individual's difficulties in ambulation, sensitivity to temperature changes, diminished vision and hearing, and impairments in fine motor dexterity. Further, training offered to staff related to physical aging and special medical and nursing care practices can also help in maintaining the older persons in his or her residence.

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[7] Readers are referred to *Guardianship of Adults (Resource Manual and Participant's Guide)*, a working guide issued by the Oklahoma Department of Human Services (Sequoyah Memorial Office Building, P.O. Box 25352, Oklahoma City, OK 73125; telephone 405/521-6254). This guide was developed by Therapeutic Concepts, Inc. for the Department as a training aid to the Oklahoma Guardianship Act.

[8] For a review of the research related to interaction of the aging process and mental retardation see *Aging and Developmental Disabilities: Challenges for the 1990s*, the proceedings of the Boston Roundtable on Research Issues and Applications in Aging and Developmental Disabilities, available from the Special Interest Group on Aging, c/o American Association on Mental Retardation, 1719 Kalorama Road, N.W., Washington, DC 20009.

The increased heterogeneity of persons in congregate settings presents an ever-expanding range of needs to be met and services to be provided by staff perhaps more accustomed to attending to a more homogeneous clientele. As people grow older, different demands are placed upon staff. In addition, the environment may severely limit function and thus, may be no longer appropriate for the older person. This challenges the staff to accommodate to changes in individuals as they grow older. Activities directed toward adapting the residence and re-training the staff rather than forcing a change in residence are much more functional means of addressing "aging in place."

☐ ***Plan considerations***

- ☐ *Has the plan addressed the need to adapt the physical aspects of community dwellings?*
- ☐ *Has the plan considered the need to re-train staff when the persons for whom they care become old?*

Transitions and transfers

Planning for transitions or transfers can involve anticipating the future needs of the population that presently lives at home or with caregivers. It can also involve state policies and planning for older persons currently residing in state institutions or in nursing facilities. This includes planning for de-institutionalization resulting from state residential facility closure and discharge of persons adjudged under the Nursing Home Reform Act as inappropriately placed in nursing facilities.

Transitioning or movement from home occurs usually in two circumstances, precipitous or planned. In the *precipitous situations*, the parent (or parents) may die or become hospitalized and no one is left to care for the older person with a developmental disability. Consequently, immediate emergency housing has to be found, resulting in less than an ideal setting. It is a circumstance becoming more frequent. In *planned situations*, the family has worked with an agency to identify acceptable options for housing. The older adult with a developmental disability participates in the decision making process, often visits the housing chosen, and transition occurs.

In either of the two instances noted above, planning for such transitions takes special care so that emergency placement options are available and a sufficient number of community living spaces have been developed to anticipate the annual demand presented by the growing elderly population.

Studies have indicated that a large proportion (sometimes up to 60%) of known older persons with developmental disabilities are currently institutionalized. In most instances the institutionalization took place when the individuals were young; not many older persons with a developmental disability are now admitted to public residential care institutions. However, those individuals still remaining in institutions may pose a special planning problem with regard to transitioning. Their length of stay in the institution has often acculturated them to the facility and movement to another, less well known, setting can pose special problems. These problems may include the unwillingness of the individual to move, finding the "right" residential and day program mix in the community, and attempting to keep intact the friendship network that the individual has developed and upon which he/she relies; thus, minimizing "transfer trauma."

☐ ***Plan considerations***

- ☐ *Has the plan addressed the need to plan for the eventual transition from living with one's family to another community setting?*
- ☐ *Has the plan considered alternatives when the state is still actively involved in a deinstitutionalization effort?*

Retirement concerns

There are numerous planning challenges related to retirement. One problem is that while it is easy to "retire from" it is not that easy to "retire to." Among persons unaffected by disability, the *primary gain* associated with work, a salary, is usually substituted by Social Security benefits or a pension. Further, most persons, when considering what to do upon leaving the workforce, also think in terms of what will replace work and the *secondary gains* associated with the work place, such as friendships, a place to go, and the personal identity that is defined by one's job. This notion of replacement leads to "retiring to." Many states have not yet developed a policy that permits individuals with a lifelong disability to retire from programs or activities in which they may have been involved for all or part of their adult life and move to another set of programs that encompass alternative facets of retirement.[9] Thus, a primary concern in state planning for retirement is ensuring that appropriate policies and structures are in place to ease retirement. Another concern is underwriting the costs of programs that aid in the transition to retirement and of programs that can maintain retirement.

An additional challenge is providing the financial supports for retirement activities. In some instances, this involves finding a way to pay for housing and day services; in others it may mean finding ways to fund pensions[10]. In still others, it may mean planning for a range of long-term care services to accommodate older persons as they become frail and more infirm with increasing age. Another challenge is how to prepare options from which seniors can chose. This may mean reconfiguring services to more appropriately accommodate people who may wish to retire to other activities.

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[9] See *Retirement Planning for Older Persons with Developmental Disabilities*, available from the UMKC Institute for Human Development, 2220 Holmes Street, 3rd Floor, Kansas City, MO 64108-2676.

[10] See *On the Feasibility of Different Pension Support Systems for New York State Residents with a Developmental Disability* (available from the New York State Developmental Disabilities Planning Council, 155 Washington Avenue, Albany, NY 12210). The report, noting that pensions contribute to the self-sufficiency, pride, and independence of a retiree, also notes that as a result of flaws and shortcomings in existing laws and procedures, older persons with developmental disabilities are generally cut off from pension plans that signify and

Planning also needs to consider which avenues of retirement should be available within the developmental disabilities system and which should be available within the generic aging network. In either case, it should include activities available to all seniors in the local community.[11] Planning should also address the absorption capacities of activities in senior centers, congregate meals sites. It should also consider alternatives that will accommodate new retirement program models that will have to be available to meet the needs of an ever increasing senior population with special needs. Planning should also look at how seniors are defining lifestyle changes and what needs to be done to help them adapt to their chosen lifestyle.

Planning within the area of retirement needs to look at policy and financing, as well as programmatic, education/training, and self-advocacy issues.

☐ *Plan considerations*

☐ *Does the plan consider retirement policies and options?*

☐ *Does the plan examine and consider retirement programs or supports?*

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ease the transition from a life centered on work-related activities to one given over to leisure activities. The report's approach is to look at four categories of workers with differing degrees of disability, each representing a different aspect of the problem. The report also looks at different approaches to pensions that could provide a quantitatively small, yet symbolically significant income during a retiree's old age. It is argued that such pensions should be seen as supplementing SSI and SSDI, which presumably will continue throughout the lives of the retirees, and will provide the discretionary income previously earned through a job. However, one problem is that to qualify for SSI, a worker must have no more than $2,000 in assets, a figure that includes tangible assets such as cash savings, stocks, or bonds (but excludes a home and other like personal effects). This asset limitation effectively proscribes lifetime savings designed to provide a "pension" payout upon retirement. The report proposes five different potential approaches to providing pensions for older persons with developmental disabilities. They are: (a) an individual "bonus check" program awarded by an individual agency; (b) a payment program financed through a surcharge assessed on commercial customers by sheltered workshops; (c) a statewide pension program administered by a statewide agency or association of agencies; (d) a variation on the standard Individual Retirement Account (IRA); and (e) a pension fund administered statewide by a private insurance company and supported through contributions from participating service agencies. With regard to (d), the report notes that current laws characterize IRAs as savings programs, and since they are counted as assets toward the $2,000 cap for individuals receiving SSI such IRAs are not available as pension plans for Americans with developmental disabilities. The report recommends changes to the Social Security law that would either change the asset cap or institute an IRA Pension Program specifically for people with lifelong disabilities.

[11] Readers are referred to the companion how-to guide, *"The Wit to Win: How to Integrate Older Persons with Developmental Disabilities into Community Aging Programs,"* available from the New York State Office for the Aging, Agency Building Two, Empire State Plaza, Albany, New York 12223-0001.

Developing plans and reports

Planning can be done within the structure of state agency or quasi-public special task forces, committees, planning councils, provider associations, and the like. Any or all can work to produce information and documents that target the specific needs of older persons with developmental disabilities. A number of informal planning documents have been produced that represent state/local task force reports or commissioned studies or reports.

The table on pages 66-68 provides information on some sample state task force reports, regional or special purpose study reports, and commissioned studies/reports. These and others like them can be used as guides for the development of your plan or report. The table provides information on the title and author, as well as purpose and contents. In most instances, these plans or reports can be obtained by contacting the organization noted.[12]

A brief synopsis is provided for each document. *System assessment* means that the document contains an analysis or assessment of the services available and needed and draws conclusions as to the barriers or systemic deficits that may be present. *Background/demographics* refers to the information the document provides on the state and its population. *Recommendations* means that the document offers next steps or actions to be undertaken. The documents' contents vary; some contain more detail, others less.

☐ *Approaching planning*

The table on page 70 offers an outline of information to include in a typical plan document. Planning does not have to be a complicated matter; it can be undertaken informally by a few persons or can be conducted formally and involve an official process. Consider the following:

- ☐ *agreeing upon terms, definitions, and scope of work*
  - *who are you going to include in the plan? (i.e., how will you define your target population; will you use the federal definition of developmental disabilities, a state variant, or some other?)*
  - *what age groups will you use? (age 55+? age 60+? no age point?)*
  - *consistent in use of terms? (for example, "aged," "older;" "elderly")*
- ☐ *gathering data on the population*
  - *request data from state agencies*
  - *conduct surveys*
  - *draw from existing documents*
- ☐ *collecting ideas about issues/problems/ solutions from key informants*
  - *interview key state agency personnel*
  - *interview key consumers representatives*
  - *interview selected service providers*

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[12] Copies and more information may also be obtained from the University of Akron's National Research & Training Center Clearinghouse, University of Akron, Consortium on Aging & Developmental Disabilities, Institute for LifeSpan Development, 159 Carroll Hall, Akron, OH 44325-5007; telephone 216/972-7956 or fax 216/972-6990.

STATE PLANS AND REPORTS

Report	Author/Source/Descriptors
State task force reports	
Serving Older Persons with Developmental Disabilities in Arizona (June 1987)	Arizona Division of Developmental Disabilities (220 North Leroux Street, Flagstaff, AZ 86001) 77 pp. Purpose: identify special situations and requirements of older persons with developmental disabilities and offer recommendations. Contains: • system assessment • recommendations
Aging/Aged Persons with Developmental Disabilities in Indiana: An Interagency Planning Task Force Report (November 1987)	Indiana University, Institute for the Study of Developmental Disabilities (2853 East Tenth Street, Bloomington, IN 47405) 46 pp. Purpose: identify special situation and requirements of older people with developmental disabilities and make recommendations for service development. Contains: • background/demographics • system assessment • recommendations
Report of the Committee on Aging and Developmental Disabilities (New York) (November 1983)	New York State Office of Mental Retardation & Developmental Disabilities (44 Holland Avenue, Albany, NY 12229) 86 pp. Purpose: examine issues, problems and needs of older persons with developmental disabilities and outline specific recommendations for addressing concerns identified. Contains: • background/demographics • system assessment • recommendations
Services for Elderly Mentally Handicapped Mississippians: A Coordinated Plan (June 1986)	Mississippi Department of Mental Health (Boswell Retardation Center, P.O. Box 128, Sanatorium, MS 39112) 113pp. with appendices Purpose: assess state of service provision, identify needs and gaps in services, define funding, and provide recommendations for state activities. Contains: • background/demographics • system assessment • recommendations
A Guide to the Future: Services to Older Persons with Developmental Disabilities (North Carolina) (March 1991)	North Carolina Department of Human Resources (Division of Mental Health, Developmental Disabilities and Substance Abuse Services, 325 North Salisbury Street, Raleigh, NC 27603) 180pp. with appendices Purpose: provide a compendium of information on state's situation related to older citizens with developmental disabilities. • background/demographics • system assessment

Nebraska Plan for Aging Individuals with Developmental Disabilities (1991)	Nebraska Department on Aging (P.O. Box 95044, 301 Centennial Mall-South, Lincoln, NE 68509) 82 pp. Purpose: evaluate current service delivery system as it applies to older Nebraskans with developmental disabilities and make recommendations for system reform. Contains: • background • system assessment • recommendations
Service for Older Persons with an Intellectual Disability in the State of Victoria (Australia) (November 1990)	State of Victoria Intellectual Disability Services, Community Services Branch (555 Collins Street, Melbourne, Victoria 3000 Australia) 60 pp. Purpose: assess state of older population of persons with developmental disabilities and make recommendations for service development and coordination. Contains: • demographics • system assessment • recommendations

Regional/special purpose reports

The Newest Minority: The Aging MR/DD Population in Oneida County (New York) (June 1988)	Oneida County MR/DD Task Force Committee (Institute of Gerontology, Utica College, Burrstone Road, Utica, NY 13502) 30 pp. Purpose: examine problems in the service delivery system of Oneida County affecting older persons with developmental disabilities. Contains: • demographics • system assessment • recommendations
Care for Aging Persons with Mental Retardation: A Planning Study for Cedar Lake Lodge, Inc. (Kentucky) (June 1990)	Urban Research Institute, (College of Urban and Public Affairs, University of Louisville, Louisville, KY 40292) 91 pp. Purpose: provide a long-range plan for older persons living at Cedar Lake Lodge. Contains: • demographics • system assessment • recommendations

Commissioned studies/reports

The Interaction of Aging and Developmental Disabilities: A Planning Study of the Aging and Elderly Developmentally Disabled (Florida) (November 1988)	Florida Developmental Disabilities Planning Council (Evaluation Systems Design, Inc., 700 North Calhoun, Suite A-3, Tallahassee, FL 32303) 99 pp. Purpose: provide descriptive information, data analysis, and planning related recommendations on Florida's older population of persons with developmental disabilities. Contains: • background/demographics • system assessment • recommendations

Planning for the Future: Meeting the Needs of Elderly Developmentally Disabled Persons: Summary Report (Massachusetts) (April 1988)	Massachusetts Developmental Disabilities Council (Heller Graduate School, Brandeis University, Waltham, MA 02254) 44 pp. Purpose: survey service system for older persons with developmental disabilities in Massachusetts, assess current system and make recommendations for service development. Contains: • background/demographics • system assessment • recommendations
The Aged and Aging Developmentally Disabled in Virginia: A Preliminary Report (October 1990)	Board of Rights for Virginians with Disabilities (Virginia Institute for Developmental Disabilities, Virginia Commonwealth University, Box 228 MCV Station, Richmond, VA 23298-0228) 51 pp. Purpose: determine population of older persons with developmental disabilities in Virginia, identify service needs, and coordinate state agencies' efforts to address needs. Contains: • demographics • system assessment • recommendations
Caring for Aging Developmentally Disabled Adults: Perspectives and Needs of Older Parents (Colorado) (September 1988)	Colorado Developmental Disabilities Planning Council (Gerontology Program, Department of Human Services, University of Northern Colorado, Greeley, CO 80639) 40 pp. Purpose: determine information about older persons with developmental disabilities living with parents or other caregivers, identify services used and needed, and identify future needs. Contains: • demographics • service assessments • recommendations
Aging Persons with Developmental Disabilities in Hawaii: Preliminary Observations (June 1989)	University of Hawaii University Affiliated Program for Developmental Disabilities (1776 University Avenue, Wist Hall 211, Honolulu, HA 96822) 48 pp. Purpose: preliminary examination of the status of elderly persons with developmental disabilities in Hawaii. Contains: • demographics • system assessment • recommendations
Aging and Developmental Disabilities: Research and Planning (Final Report to the Maryland State Planning Council on Developmental Disabilities) (April 1987)	Center on Aging (University of Maryland, College Park, MD 20742-7321) 100 pp. Purpose: identify current status of state's population of older persons with developmental disabilities, identify their needs and the barriers to receipt of services, and develop recommendations for overcoming the problems identified. Contains: • demographics • system assessment • recommendations

- *beginning to select the key issues*
  - *what are the most pressing concerns?*
  - *what are barriers that should be addressed quickly?*
  - *what are barriers that call for long term actions?*

- *developing a working draft and circulate it broadly for comment*
  - *include persons not originally contacted or involved*
  - *include persons quoted or whose information you used*

- *incorporating suggestions from readers*
  - *consider political ramifications of changes – will they help in acceptance of report once it is formally distributed?*
  - *consider whether changes will help in stating your goals*

- *making changes for readability*
  - *size up print, use white space, wide margins, avoid overly jargon-ridden text, use illustrations and charts, bold and highlight recommendations.*
  - *include tables that can be easily photocopied for local plans.*
  - *follow the "KISS" admonition: "Keep It Short and Simple"*

- *deciding on distribution*
  - *include a transmittal letter from highest government official*
  - *include brief summary in front that highlights findings and recommendations*
  - *distribute broadly*

☐ *Undertaking a needs assessment*

To determine what may be needed by a target population, it may be necessary to undertake a needs assessment. Undertaking a needs assessment also serves to sensitize those involved to the issues and can serve as a means of creating a network of interested persons. The value of this largely unintended result should not be underestimated.

Needs assessments may be done via a formal or informal process. Planning at the state level to prepare a state or federally mandated plan document is usually a formal process, involving specific dictums, examining and projecting the allocation of resources, and identifying products linked to legislative or agency policy initiatives. Alternatively, informal processes can be simply the assembling of what information is at hand, making it available through whatever channels exist, and incorporating it into a report or plan document.

NEEDS ASSESSMENTS SHOULD

- *systematically identify the population under study.*
- *provide reasonable estimates of the number and scope of the population.*
- *determine the resources currently available to address the population.*
- *identify the needs of the individuals within the population.*
- *identify means to satisfy these needs.*
- *identify possible barriers meeting these needs.*

Whichever means are used, a needs assessment can aid in planning because it helps to define or determine the following:

- the number and characteristic of the population under study,
- which services are most needed or are in most demand,

- to what extent the services already available address these needs (i.e., the issue of availability),[13] and

- the extent to which available services are coordinated and accessible to persons needing them (i.e., the issue of accessibility).[14]

To aid a planning effort, there are two primary strategies that can be used to collect information:

- *Hard data collection*: This strategy involves using appropriate means to obtain information about certain social characteristics of a population and/or ecological characteristics of an environment to rates of a condition. Such approaches include epidemiological research, social and health indicators analysis, and uses of an approach termed "rate-under-treatment".

Sources of hard data include:

- state agencies that maintain "client information systems."
- universities that have undertaken specific surveys.

WHAT TO INCLUDE IN PLANS OR REPORTS

Background Information
- *statement of intent, values, philosophy*
- *what's to be discussed*
- *define the problem*
- *define the agencies involved*

Demographics
- *what information is available on state's older population*
- *what information is available on state's older population of persons with developmental disabilities*
- *population projections (current, near future, long range)*
- *population charts/tables by cities, counties or service districts*

Service Availability and Accessibility
- *discussion of current conditions in state*
- *discussion/identification of impediments to achieving desired ends*
- *discussion of population needs, agency needs*

Strategies and Recommendations
- *presentation of strategies to overcome barriers*
- *discussion of trends and needs to be addressed*
- *succinct recommendations of report*

Appendices
- *bibliographies and references*
- *reference matter*
- *tables, charts*
- *agreements*
- *lists*

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[13] *Availability* refers to the presence of a service; this may be expressed in terms of whether a service exists or in degrees -- whether sufficient program spaces [or some other measure] exist. The planning question is whether supply equals demand.

[14] *Accessibility* refers to the ability of an older person with a developmental disability to obtain needed services; this may be described in terms or whether the service exists and the extent to which barriers are present to obtaining the service. Accessibility may be affected by a variety of factors: *economic* (agencies lack funds to provide or the person can't pay for it), *temporal* (not provided during times when needed), *locational* (the person can't get to it), *architectural* (building design prevents access), *organizational* (language or cultural difference; not designed for all) or *informational* (don't know it's there).

- health systems or planning agencies that maintain extensive databases or information on population health status.
- service providers' data.

- *Soft data collection:* This strategy uses subjective evaluations of developmental service needs obtained from a variety of knowledgeable and representative informants.

Sources of soft data and information include:

- mail and telephone surveys.
- information drawn from state policy documents and plans.
- annual reports and newsletters from consumer organizations.
- interviews of key informants.

Most organizations will lack the resources to undertake rigorous scientific studies of the characteristics and needs of specified populations (for example, all older persons of a state). However, if the resources are available, such studies, on a population or sample basis are ideal and can provide much useful information. When such projects are not easily undertaken, other methods can be employed to collect useful information. Such methods, which can be carried out with less time and expense can include mail and telephone surveys. The next section covers these methods.

☐ *Conducting mail surveys*

One means of collecting information is to mail out a survey form that requests responses to your questions. Before attempting such a survey consider:

☐ *thinking about how the recipient of your survey is likely to respond to the survey (is it seen as important or as another piece of "busy-work")?*

☐ *asking for information that will take no more than 10 minutes to find; don't send a form that will take more than 15 to 20 minutes to complete.*

☐ *asking for simple rather than complex information (for example don't ask, "How many persons do you serve who are age 65 and older who come from the Eastside, how often do they come, and who brings them?").*

☐ *keeping your questions simple (for example, "In your estimate, what percentage of your clientele are men?") and remember most agenciesdon't have the means to keep formal data or the means or time to retrieve data that may be in user records.*

☐ *giving your respondents options to chose from, rather than asking them to write responses (for example, "What percentage of your program participants are men?: none, less than half, half, more than half, all).*

☐ *using a survey form that is easy to complete. In most instances, this means not requiring a written response. Using multiple choice items will make it easier later to code the responses and simplify your analyses.*

☐ *giving the recipient space at the end to tell you some of his/her thoughts;*

however, make this an optional part of the survey.

- *working out the codings in advance, not after you get the surveys back, if you are going to computerize your data.*
- *pilot testing your survey.*

☐ *Conducting telephone surveys*

Another means of collecting information is to telephone key people or informants. Before making your calls, consider:

- *testing the questions and modify them to make them useful and understandable.*
- *sending a letter ahead of time telling the person you will be calling and enclose questions to be answered*
- *having questions prepared and standardized before you call.*
- *asking open-ended questions and code them as you hear the responses.*
- *asking follow-up questions to amplify the respondent's thoughts on issues.* ☐

Section 7

Building Partnerships

Partnerships between the aging and developmental disabilities networks are essential to the expansion and improvement of services to older persons with developmental disabilities. Developing such partnerships can involve a number of approaches. This section presents some suggestions about how to bring the aging and developmental disabilities agencies together, techniques to organize your community, and methods to develop interagency agreements.

Partnership initiatives by state councils or advisory bodies

One path to developing a partnership can be through the adoption of such an initiative by the developmental disabilities planning council. This can be accomplished in the following way:

- the council, through its members -- the aging agency administrator and the mental retardation/developmental disabilities agency administrator -- can seek to target aging/elderly persons with mental retardation/developmental disabilities as one of its priorities. This can lead to an interagency committee being set up with the charge to conduct conjoint planning, budgetary allocations, and staff sharing arrangements.
- the developmental disabilities planning council can, through its

grant program, offer funding support to the state unit on aging to do policy studies, conduct needs assessments, and/or establish demonstration programs that draw together local aging agencies and the community's mental retardation/developmental disabilities providers.

The state advisory council on aging can reach out to the state developmental disabilities agency and establish an interagency task group that would be charged with coordinating planning, training and services development. It can also ensure that a person or persons representing the interests of older persons with a developmental disability will become a member of the council or advisory body.

Partnership initiatives by state agencies

Using an interagency task force is a helpful initial approach. The state unit on aging can reach out to the state developmental disabilities agency and establish an interagency task group that would be charged with coordinating planning, training and services development. The developmental disabilities state agency can reach out to the state's unit on aging agency and establish an interagency task group that would be charged with coordinating planning, training and services development.

☐ ***Techniques that bring state officials together***

- *inviting comparative level administrators from the aging and mental retardation/developmental disabilities to speak to a provider/consumer group or at an interagency conference.*
- *inviting representatives of aging and mental retardation/developmental disabilities to be on a planning committee for a conference or task group on aging and disabilities.*
- *working toward formalizing a relationship among the aging service agencies and mental retardation/developmental disabilities agencies, and the state's developmental disabilities planning council through mutually agreed upon roles and responsibilities that stem from an interagency memorandum of understanding.*
- *working toward establishing an interagency task group that examines a particular long term care problem (e.g., housing, adult day care, family assistance) that involves both dependent elderly and older disabled populations*

Organizing your community

There are a number of aspects you should consider when organizing a community to meet the needs of older persons with developmental disabilities. These include:

- ***Is there an estimate of the number of older persons with developmental disabilities in the community?*** If not, what can be done to obtain either an estimate of the older population of persons with developmental disabilities or a working head count? Are there university or governmental resources available to obtain this information?

- ***Have disabilities providers accepted the fact that they have a significant number of older individuals being served by their agency, and do they think that a differential program approach is warranted and necessary?*** If there is denial of the problem, what approaches can be used to help the agencies recognize and accept the need?

- ***What is the position of the area agency on aging with regard to the community's older disabled population?*** Is it an attitude of "we'll try to do what we can..." or "they're not our responsibility and you keep them..."? Have overtures been made to collectively approach the problem? Is this negative position a result of "handicapism" with regard to mentally retarded or physically disabled people or a general attitude toward any problematic population? Is it the position of the senior administrator or indicative of the whole agency? Is it likely to be overcome with education and overtures to share responsibilities and resources?

- ***What are the disability agency's program attitude structures like?*** Are they generally isolated and overwhelmingly encompassing or do they encourage and facilitate independence and community integration? Do the disability agencies try to do it all or perform the role of a broker and facilitator for persons to use other community services? Is the attitude one that is historical in the community or is it based upon the prevailing attitudes of the board of directors? Can the attitude be modified?

- ***What are the activities of self-advocacy groups?*** Have local self-advocacy groups organized to help the older members of their group? Has the locality's independent living center been involved with the aging network to work on issues of physical accessibility or program integration? Are there groups that could be formed to provide mutual assistance and supports? How will persons with impairments be represented in your efforts?

- ***What are the transportation resources for other elderly or disabled persons with special needs?*** Is your area able to make use of public transportation or is this a serious problem for all local residents? Do the aging agencies have their own transportation resources? Do the disability agencies have their own? Are they agreeable to sharing transportation resources and helping each other in the event of duplicative routes?

- ***Do program regulatory structures seem to discourage innovation***

in program design for special population groups? Is the attitude of state authorities one of flexibility or rigidity with regard to the program standards for special situations? If there is a problem, is the problem one of written policy and procedures or regulations, or of historical practices that have become hard to change? Has anyone tried with regard to senior services?

- ***Do agencies feel that they can start up new programs with state or other financial assistance or are new programs not allowed at this time?*** Is start-up of a new program a lengthy and laborious process? What is the budget climate like? Are there start-up or demonstration funds available that could be used for senior services?
- ***What is the nature of the senior center and congregate meal sites in the community?*** Are the centers dominated by a clique (a closed group) of seniors or are they generally open to all potential users? What are the integration potentials of the sites? Who has the final say on methods of access? Are there other seniors who would be willing to serve as senior friends or companions to new members from the disability agencies?

Strategic planning to organize the community involves the consideration of these and other variables by a committee made up of people from both the aging and developmental disabilities networks. How these questions are approached within the context of a partnership building effort will often dictate how successful the committees efforts will be.

Setting up local task forces

Networking and networking meetings made up of people from both the aging and developmental disabilities networks set the stage for building the relationships needed to make integration a reality. One way to network is to organize a workgroup, committee or task force. The setting up of such formal committees or task forces should be a precursor to other activities when your focus of activities is in a highly urbanized metropolitan area. Rural areas, composed of few agencies and interested or affected staffers, can come to cooperative decision-making over a meal at a local restaurant. However, highly urbanized areas, with a complexity of staff interactions, agency territories, and disparate funding and oversight sources, may need a more structured brokering approach. Such formal task forces are generally set up to achieve a specific aim -- such as new program development, interagency cohesion, or promotion of accessibility.

If your needs are to organize such a formal group in a major metropolitan center, we would suggest that you follow the suggestions outlined, but direct your activities in a more formal manner. For example, to get such an effort off the ground, you may need a formal auspice -- that is, the sanction and support of a formative group whose reputation and role is such that it will draw participants to the task force. In some instances, the charge to such a group comes from a geovernmental or other entity.

Such an entity might include:

- the local government mental health or mental retardation/developmental disabilities department
- the local county aging office or department
- a university center on developmental disabilities or gerontology/geriatrics
- a foundation
- a community planning body or interagency council
- a health systems agency or similar group

A formal approach generally may be needed to set up the such a group. Before getting to far along, consider the following:

☐ *sending invitation letters which are on the letterhead of the sanctioning organization to the involved agencies and their representatives.*

☐ *thinking ahead about specifically who to invite who will "spark" discussions and keep them within the objectives of the group.*

☐ *obtaining a "charge" or directive from a governmental entity to enable you to coalesce the agency participants around a tangible objective.*

☐ *appointing a formal chair or convener appointed (from either the group or by the sponsor) to help lead the meetings and keep the agenda on task.*

☐ *dividing your large group into committees that are charged with specific tasks.*

☐ *recording attendance and minutes of meetings and distributing them in a timely manner prior to ensuing meetings.*

☐ *developing "carrots" or incentives to keep participants involved (these might include helping design a short and long range plan, recommendations for budget requests or allocations, publicity or public education campaigns, legislation review and lobbying, needs assessments, policy review and publicity and recognition for their agencies).*

☐ Developing local aging & developmental disabilities networks

Local aging and developmental disabilities networks are the informal groups formed by persons of like interest or concerns. The importance of helping to foster a local network is highlighted by the successes they have had in promoting community integration. A network group can be the driving force behind integration, helping to carry out activities and mobilizing the greater community behind their efforts.

In many communities, working network groups have lead to or have been formed from task forces of agencies/providers in either the developmental disabilities system or the aging network. Similar efforts can be made to establish *regional* joint network groups on aging and mental retardation/developmental disabilities. Network development strategies can be broken into **informal** and **formal** approaches.

Within the ***informal*** or grassroots approach, the impetus for building a network comes from one or more personally committed individuals who are concerned about the issue. This approach can produce an informal network that can sprout from a meeting process that involves like-minded individuals who have come together to share ideas.

Meetings held to share information and to develop local community service development strategies can be one outcome. These informal network groups can eventually lead to more formal provider associations, or community planning bodies. Informal network development can involve the following:

- *raising the issue at a staff meeting within your agency and suggesting that you would like to lead a study group to discuss it further.*
- *asking if others, at an interagency meeting of providers, are interested in setting up a committee on aging.*
- *finding out who in other agencies which operate seniors programs should be involved by writing to agencies in your area and inviting interested persons to an informational meeting on the subject.*

The ***formal*** approach is more structured and includes contacting a wide range of agencies that serve older persons and persons with developmental disabilities in the target community and speaking with the persons in charge of those agencies, as well as leaders of consumer groups or local planning bodies.

The primary contacts should, at minimum, include a number of different persons and groups. Consider contacting:

- *professionals who work with older persons with developmental disabilities, such as social services workers and the managers of residential, work, and day programs.*
- *government agencies with responsibility for persons with developmental disabilities.*
- *private organizations, such as foundations and charitable funds, active in the community that are concerned with the elderly or with developmental disabilities.*
- *caregivers for people with developmental disabilities. These would include families of individuals with disabilities, foster families, community residence operators, and anyone else who voluntarily or in a familial or professional role provides services to persons with developmental disabilities.*
- *operators of programs for the elderly such as congregate meal sites, senior centers, day care centers, and other programs.*
- *other influential community providers such as physicians and health care workers who come in contact with persons with developmental disabilities.*

Critical to either method is the commitment of the individual(s) who begin the effort. It is the individual investment of time, energy, and personal sacrifice that will often tell of the success or failure of a networking effort.

However, such efforts seldom begin and build in an idealized fashion. Discouragement can be experienced, stemming from such diverse sources as agency territorial politics, government inertia, seeming indifference by professionals not yet "tuned in" to the realities of the aging population, and personality conflicts. These seemingly insurmountable obstacles will become mere hindrances if one perseveres in the network building processes.

Interagency agreements and relationships

The purpose of an interagency agreement is to bind two or more agencies to a common purpose and to clearly delineate the roles and responsibilities of each. Interagency/intergovernmental state/local agreements can be useful defining activities and identifying a common goal.

An example of such an agreement is the one that has been signed and implemented at the Federal level between the Administration of Developmental Disabilities and the Administration on Aging (a copy of the agreement appears in Appendix C). Such agreements also may be signed at the state, regional and local levels.[15] Examples of such agreements are also in Appendix C. These agreements may address any or all of the following actions:

- encourage the staff of each agency to consult and to share expertise, creatively solve common problems, and advocate for services;
- plan and implement appropriate models or demonstration programs;
- exchange information and data;
- use cooperative funding opportunities available from federal agencies and private organizations;
- plan for future needs;
- identify current gaps in services;

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[15] A number of states have signed interagency agreements, including California, Connecticut, Illinois, Ohio and New York. Examples of New York's state and local agreements are in Appendix C. For copies of the other states' agreements, contact the following: California Department of Developmental Services, 1600 9th Street, Sacramento, CA 95814 or California Department of Aging, 1600 K Street, Sacramento, CA 95814; Connecticut Department of Mental Retardation, 90 Pitkin Street, East Hartford, CT 06108 or Connecticut Department of Aging, 175 Main Street, Hartford, CT 06106; Illinois Department of Mental Health and Developmental Disabilities, 402 Stratton Office Building, Springfield, IL 62706 or Illinois Department of Aging, 421 East Capitol Avenue, Springfield, IL 62701; Ohio Department of Mental Retardation and Developmental Disabilities, State Office Tower, 30 East Broad Street, Room 1280, Columbus, OH43224 or Ohio Department of the Aging, 50 West Broad Street - 9th Floor, Columbus, OH 43266-0501.

- develop joint annual workplans;
- consult on development of state or local plans;
- encourage cooperation and coordination of services between regional/local aging and developmental disabilities agencies;
- coordinate public education and awareness campaigns;
- develop guidelines for senior program requirements and regulations;
- develop guidelines for pre-service and in-service training and education programs in aging (gerontology and geriatrics) with application to disabilities;
- adopt an agreed-upon, standardized system of data gathering and bookkeeping;
- develop and deliver joint testimony before legislative or budget bodies or committees; and
- make recommendations for legislative action.

What comes first, agreements or cooperation? This will depend greatly upon the circumstances in each state and locality. In our experiences, we have found that cooperation leads to agreement. This permits time to test out areas of concern where an initial formal arrangement may be an hinderance. However, in other instances, such cooperation would not start without a formal agreement.

☐ *Setting up an interagency agreement*

Consider:

☐ *starting by meeting with the individuals from the other group or agency.*

☐ *developing a common agenda and timeframes*

☐ *agreeing that there is a need to formalize your relationship*

☐ *identifying items that need to be included in the agreement*

☐ *analyzing the ramifications of the items and the wording to be used to identify and formalize them.*

☐ *developing a working draft for consideration by all principals and interested parties.*

☐ *circulating the draft for comment to key individuals/agencies/groups*

☐ *ensuring that you have the full support of the signatories before you proceed further.*

☐ *incorporate appropriate changes derived from comments.*

☐ *circulating the final version one more time for "last chance" comments.*

☐ *gathering signatories and holding a signing ceremony.* ☐

Section 8

Developing Training and Education Programs

Integration succeeds when program staff understand and feel competent in addressing the needs of their clientele. Staff must understand disabilities and issues related to aging and the loss of functional capabilities related to advancing age.

Training programs are an important ingredient for project staff managers and direct care staff responsible for providing programs and care to older persons who have a developmental disability. These programs should blend the available expertise found in gerontology and geriatrics programs with the expertise found in developmental disabilities programs. Other disciplines, as appropriate, can contribute to training and education programs.

Training will help staff to:

- learn about all aspects of the aging process as it applies to persons with a developmental disability, and about the community services available to such persons;
- know how to identify older people with a developmental disability who can be integrated into aging services programs and sites that can accept them;
- know the procedural steps needed to bring about effective integration;

- know how to oversee and evaluate the integration activities;
- understand the general functional aspects of the older person with a developmental disability;
- work with the specific individuals being integrated into an aging program site; and
- overcome apprehensions about working with older persons with a developmental disability.

Who should be trained and what type of training is needed? How should that training be delivered and what is the best methodology to do so? How can you determine what groups should be targeted and how can you be sure that the training you provide is effective?

Determining training needs

According to a report prepared by the National Institute on Aging[1], the following health care fields will need training in the needs of older persons with developmental disabilities between now and the year 2020:

- medicine
- nursing
- dentistry
- psychiatry
- psychology
- social services
- occupational and physical therapy
- pharmacology
- nutrition
- recreation/leisure therapy, and
- communication therapy

In addition, there is a need for a greater number of specialized university programs to offer training that combines mental retardation/developmental disabilities education with aging and geriatric education.

In order to address these needs, it is important to discern between short term and long term training needs. For the short term, there is a need to train service providers and caregivers who already work with older persons with developmental disabilities. To accomplish this, we need to expand short-term training efforts to:

- increase the number of currently employed practitioners with expertise in both the fields of aging and developmental disabilities;

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[1] *Personnel for Health Needs of the Elderly through the Year 2020*, National Institute on Aging, (Bethesda, Maryland), 1987. This report, among other things, has a section that addresses the needs for trained personnel with regard to developmental disabilities.

- emphasize aging in the training programs of key workers in the field of developmental disabilities who are currently (or will be) working with adults;
- introduce developmental disabilities content into the training programs of workers in the aging field;
- institute a systematic system of in-service training programs for workers in both fields, to ensure that even when there is staff turnover, workers will continue to be trained; and
- develop curriculum materials that can be used by trainers who do not have an in-depth knowledge of the subject matter themselves.

For the long term, there is a need to develop and train professionals entering the field of aging and developmental disabilities. In order to accomplish this, we need to :

- set up faculty leadership/fellowship programs within geriatrics and gerontology university and research programs for cross-training faculty of developmental disabilities programs;
- introduce the topic of developmental disabilities into the curricula of academic programs on aging, geriatrics, and gerontology;
- involve the efforts of individuals with expertise in aging, geriatrics, and gerontology who work within university affiliated programs (UAPs) to develop coordination between UAPs and nearby university programs in aging;
- identify, designate, and develop select UAP programs as training centers in aging and developmental disabilities;
- develop affiliation agreements between university programs specializing in developmental disabilities and university programs in aging, geriatrics, and gerontology; and
- strengthen long-term training activities to increase the number of new professionals in a variety of disciplines with knowledge of the special aspects of aging among persons with developmental disabilities.

☐ *Assessing training needs*

In Section 6 we provided information on conducting needs assessments as a basis for planning. Here, we draw on part of that material to highlight some practices used to assess short and long term training needs.

When assessing training needs, look for the following:

- gaps in human resources in the service system, including the specific skills needed to address service demands. For example, it is not sufficient to know that there are shortages of physical therapists or of other health care providers to serve aging persons with developmental disabilities. Each locality should endeavor to identify the particular set of skills that are lacking in the available human service pool that would be required to serve these persons. Such needs assessments should yield information on numbers of persons needed, as well as the skills they need to acquire.

- skills that may be required to initiate basic day and residential services. In most communities, basic services frequently require personnel at the direct care level, while less critical skills may involve tertiary diagnostic and treatment planning services.

Whom should you survey? In general, assessment of short and long term training needs requires input from service providers, training resources (such as universities and agencies which provide inservice training), funding sources such as government agencies and private foundations, consumers, and the potential trainees themselves.

How do you survey? Here are two approaches that can be used to assess training needs:

- ***conduct a formal needs assessment*** of your community's training needs by surveying the available pool of professionals or workers who provide services; the educational resources that deliver training; and other individuals involved in advocacy or development work.
- ***do consensus planning*** with a task force, such as described in Section 7. A task force or committee can be used to arrive at a list of barriers to, and needs for, effective personnel preparation in aging and developmental disabilities. This approach often complements, but may not replace the formal needs survey techniques described above. This approach has the advantage of also developing community support for a training initiative, which may not occur when the formal survey approach is used alone.

Training approaches

Training is a means of providing information to aid in enhancing skills in response to a stated need. The process starts with determining the needs that are to be addressed by the training, identifying the models that can be used to implement training, and following through with an evaluation of your efforts. This section examines a variety of training models and evaluation techniques.

There are a variety of approaches that can be used. You can

- develop cross-training/inservice training,
- organize conferences and teleconferences,
- use a "train-the-trainer" approach, and
- organize staff exchanges.

☐ *Developing cross-training/inservice training*

One of the most useful tools available to assist you in developing working relationships between the aging network and the developmental disabilities network is the cross-training approach. ***Cross-training*** is mutual inservice training on topics offered to staff in the aging network and the developmental disabilities network at the same time. An approach that has been the most effective from our experience has been to provide co-trainers, one from the aging network and one from the developmental disabilities network. This approach helps the staff that are co-training to get to know one another, helps break down the terminology barrier and assures that training is presented from the perspective of both networks.

Cross-training taps the native talent that is available in your community. While most persons do not view themselves as experts in the blended field of aging and developmental disabilities, when they are asked to participate in the design and delivery of training they begin to see that they have something to offer. Often, they develop an interest in a field that was previously unknown to them. If opportunities for informal socializing are included in cross-training, the process of networking has begun.

Cross-training can be used either as a starting point for networking or as a goal of an already established network. The advantage of using cross-training is that it helps to develop communication that is understandable between the aging and developmental disabilities networks, as well as provides a valuable resource that can be used by both networks. When training funds are scarce, cross-training can be used to improve the quality of service provision in both the aging and the developmental disabilities networks. This approach also promotes a more personal understanding among participants of each other's service network.

Consider the following when planning and developing your cross-training program:

☐ ***identifying auspices:*** *Cross-training should be sponsored equally by the aging and developmental disabilities network to avoid the perception that the training is "owned" by one network only. If possible, planning and coordination should be shared equally by representatives from both networks.*

☐ ***promoting agency cooperation:*** *If agencies from both networks can share the coordination and implementation of the training series it is more likely to be attended by staff from both networks and makes the delivery of the training less cumbersome for any one agency. This also means the expertise of staff from both networks can be used.*

- ***using common language:*** *A basic resource you will need to develop before training begins is a glossary of terminology commonly used by both networks. This will assure a common basis for understanding.*

- ***funding support:*** *With the above cooperation any expenses that are incurred can be kept at a minimum and shared by the agencies. If funding is an issue, see if a foundation can cover the cost or if a small fee for the training can be charged.*

- ***identifying instructors:*** *Instructors will need to be identified. Look for people in the networks who already have the expertise, such as a nurse who can provide health care information for the elderly. You may find expert trainers working within your local colleges or universities. Staff development departments are also ideal places to look to for instructors.*

- ***identifying staff:*** *You will need to determine who you are targeting for this training, which can range from administrators and clinicians to direct care providers. The tendency is to provide training only to direct care providers, however any successful integration requires the support of the administrators and the understanding of clinicians.*

- ***locating training:*** *A site that is located centrally, provides appropriate training space and is free to use is the most ideal. Such places as the local library, city hall or sites within the agencies themselves can be utilized for the training. You may also choose to rotate the location of training between agencies if a series of sessions are being offered. Moving from one site to another enables trainees to become familiar with a culture and setting of services other than their own.*

- ***scheduling sessions:*** *You will need to determine the number of sessions you want to offer, frequency of sessions and how close together to schedule the sessions. While there is never a perfect time to hold training you will need to determine the time when the greatest number of staff and instructors are available to attend. When you offer a series of consecutive sessions, try to keep the time and the day of the week a constant, even if you are rotating among two or more locations.*

- ***advertising:*** *To assure your sessions are well attended, you will need to advertise to the targeted staff. This can be done in a variety of ways such as through the agencies newsletters, memos within the agencies, posters, brochure announcements, local radio, TV and newspapers. With agency cooperation, distribution costs can be minimal as copying costs can be shared and mailing can be done within the agencies. A technique found to be useful is to have your senior administrators in the agencies develop letters of support of the training for distribution with the training announcements.*

- ***identifying "perks":*** *Though the training that you are offering is a resource in itself, if you can offer other benefits you will find larger attendance. These perks can be a certificate for completion of the training sessions for the staff records or continuing education credits.*

- ***evaluating:*** *Evaluations should be completed by participants at the end of each session so that you can improve or change the training to best meet the needs of attendees. You should also ask participants to list other training needs for future cross-training series. You can administer satisfaction questionnaires or you can design pre- and posttests for your training sessions. A specific time* *should be set aside after the training for the instructors and planners to review the evaluations and make decisions about future changes. Evaluation is only useful if it becomes incorporated into future planning.*

- ***mailing lists:*** *This can be one of your most useful tools. The mailing list can be developed by agencies sharing their mailing lists or obtained from special interest groups on the issues related to aging and developmental disabilities. You can start with a small mailing list and add to this from attendees at training sessions and staff who express interest in attending. It is easiest to keep the mailing list on computer so that it can be added to easily and pulled easily. To develop an accurate mailing list takes time. It is important to update it regularly and to watch for duplications and incorrect names and addresses.*

- ***developing networks:*** *Your cross-training sessions can be used as a starting point for the development of a coalition to address local issues on aging and developmental disabilities. You can set up separate meetings and announce them at the cross-training sessions or you can elicit discussion on specific topic areas brought up as a result of the training and hold mini-meetings after the sessions. Another approach is to use the mailing list developed for the cross-training and invite people from this list to a meeting. Be sure you are including administrators or at least have the support of the administrators.*

☐ *Selecting topics for training*

Topic selection is important to the success of any inservice or cross-training program. Some of the topics you will select will be based on local issues and local expertise. Others are so important that you should look at developing experts in these areas. The topics listed below have been found to provide a well-rounded level of knowledge for developing competence in program staff. Research is beginning to support the idea that there are more similarities than differences among older persons with developmental disabilities and other older persons. This should be emphasized throughout your cross-training.

Preliminary level topics most often requested and that have been the most useful according to staff feedback include:

- biological aspects of aging and its applications to developmental disabilities
- characteristics of individuals who are aging (should include service provision definitions and issues)
- characteristics of individuals with developmental disabilities (should include basic definition, types and causes of developmental disabilities, and local and national demographics)
- family issues among older persons with application to developmental disabilities
- integration/service models for older persons with developmental disabilities
- overview of the aging system (including typical terminology used as well as common acronyms used in the system)
- overview of the developmental disabilities system (including

typical terminology used as well as common acronyms used in the system)

- program activities for older individuals with developmental disabilities
- psychological aspects of aging and applications to developmental disabilities
- social aspects of aging and its applications to developmental disabilities

Once a basic level of knowledge has been developed among staff within both networks you can then look at offering more advanced topics. The advanced topics noted below can be specially helpful to staff.

Advanced level topics include:

- adaptive equipment
- Alzheimer's disease and Down syndrome
- challenging behavior
- communication needs and skills
- day services needs and options
- grief and bereavement (death and dying)
- environmental designs
- ethical issues
- functional programs for seniors who are frail or severely impaired
- health care promotion
- health care prevention
- legal aspects, guardianship, permanency planning
- leisure needs and recreation
- local issues
- medications and their side-effects
- nursing home admission and criteria
- nutritional needs
- physical fitness and exercise
- recent research on aging and developmental disabilities
- reminiscence
- residential needs and options
- retirement philosophies and practices
- seizures and medications
- sexuality
- topics requested by participants

☐ *Organizing and carrying out conferences and workshops*

Conferences and workshops are effective ways of presenting both specialty or generic information. They are relatively easy to organize and in most instances can be offered at a low cost. There are a number of tasks related to organizing a conference or workshop. You might consider the following:

☐ *assembling a conference/workshop planning group*

☐ *determining what information is to be presented*

☐ *assigning workgroup/task responsibilities to planning group members*

☐ *selecting preliminary date, time, and location*

☐ *lining up support funding*

☐ *agreeing upon timeframes and tasks*

☐ *selecting and confirming speakers and presenters*

☐ *confirming date, time, and location*

☐ *advertising broadly and including incentives for attendance*

☐ *confirming planning group member responsibilities for conference/workshop*

☐ *conducting evaluation of sessions*

☐ *conducting de-briefing meeting after conference/workshop.*

Before organizing a conference, you will need to convene a group of interested persons who will be willing to help. Be sure to include persons from both the aging and developmental disabilities networks on your conference/workshop planning committee. Have the planning group agree upon a theme and the need to secure a sponsor or sponsors for the conference. Also decide on the goal of the conference (that is, what it is designed to accomplish), and the format of the conference/workshop. Will it only impart information or will it aid in networking or both?

- if ***networking is an objective***, be sure to build in times for formal and informal participant discussions and conversations. Also be sure to give each participant a list of all participants, preferably with their addresses and telephone numbers listed. To encourage participant interactions, use name tags with very large and clear print, build in breaks for conversations, and consider a buffet lunch which tends to be a better networking tool than a fixed menu lunch.

- if ***dissemination of information is your objective***, use handouts and be sure to have sufficient quantities available for distribution. These can come from the speakers or from agencies or groups who are specifically invited to set up display tables. Also, encourage speakers to build in a discussion or information exchange period at the tail end of each session.

In planning a workshop or conference, determine early in your planning whether financial supports will be necessary. Unless you are using speakers whose travel expenses and honoraria are quite hefty, most conferences and workshops can be self-supporting through registration fees. Fees, however, should be kept to a minimum if your objective is broad dissemination of information, since many agencies are not in the financial position to reimburse staff for such fees. Fees in the $5.00 to $15.00 range seem to be the most affordable for most participants. If there are no external supports, your fees will need to cover the costs of advertising, mailings, printing, speaker reimbursements, conferences handouts (badges, programs, bags) and, if included, tea, coffee, juices, or soft drinks for breaks and lunch.

Consider using a two-tier fee structure that rewards early registration with a reduced fee, while offering the regular fee for on-site registration or registration within two or so weeks of the conference. Such an approach will permit you to better gauge your attendance and rate of sign-up for individual sessions, and make final session room assignments.

Allow sufficient time for advance notification of the date, time and location of the conference/workshop. Allow time for conference planning, mailing, and site selection. Consider using a preliminary announcement/brochure that offers potential participants information on date, time and location and an outline of the conference content. Solicit preliminary interest in attendance. A follow-up announcement can contain registration materials. Also, publicity via the local newspaper or agency in-house newsletters or bulletin board postings is very effective.

SUBJECTS MOST FREQUENTLY PRESENTED AT CONFERENCES

- *Alzheimer's disease, with specific applications to persons with Down syndrome*
- *Community and social support services*
- *Day service options, including respite, recreation, and senior programs and activities*
- *Demographics of the populations of aging persons and aging persons with mental retardation and developmental disabilities*
- *Explanations of the biological aging process, as well as the psychological and social aspects of aging*
- *Housing options and in-home supports*
- *Issues surrounding integrating the aging services network and the mental retardation and developmental disabilities services network*
- *Legal concerns, such as guardianship, wills and trusts, and protection and advocacy*
- *Physical and mental health, fitness and exercise*

A good mailing list is of the utmost importance, as are a well-designed brochure, an accessible location, and support personnel to help with mailing, registration and other logistics. Be sure your site is wheelchair accessible and otherwise barrier free. Consider the needs and sensitivities of multicultural or multilingual areas; brochures and announcements in the language of the audience you hope to attract will improve attendance.

Remember to prepare an evaluation form that participants can use to offer feedback and to use the opportunity to distribute a survey which can tap participant's desires for other training opportunities. Readers should refer to the section beginning on page 95 for information on evaluating training.

Conferences and workshops with aging and developmental disabilities as their main topic generally have sessions that can be categorized into five general content areas (see the box on page 90 for a listing of the subjects most frequently presented):

- systems of care
- social supports
- health/emotional concerns
- day/activity services and programs
- housing needs

The content areas listed above are similar to those offered within gerontological education/conference programs except that the focus is more directed toward older persons with developmental disabilities. These sessions should be of interest to participants from both the aging and developmental disabilities networks. Each of the topics can be presented as it applies to the older person and then as it applies specifically to the older person who also has a developmental disability.

If you do not wish to develop your own conference, or if funds are short, consider "piggy-backing" your conference or workshop sessions on aging and developmental disabilities in conjunction with another regional or statewide conference, thus minimizing expenses for participants and making use of special group discounts for travel, lodging and meals. Another useful workshop resource can be found in an educational center or agency. For instance, most local departments of aging, gerontology centers and large agencies sponsor training sessions and it may be possible to work with staff to focus one of these sessions on aging and developmental disabilities content. Offer to provide speakers and to assist with organizing the conference sessions in return for help with space, mailing, support staff, and the like.

☐ *Obtaining funds for underwriting a conference*

In many states, the following organizations can be useful resources for conference funding and co-sponsorship:

- state developmental disabilities planning council
- university affiliated programs in developmental disabilities
- university based centers on aging
- geriatric education centers
- interagency councils or consortia
- state agencies on developmental disabilities
- state agencies on aging
- state chapters of national groups[2]
- state gerontological societies
- provider or vendor associations
- provider and social service agencies
- hospitals and other institutions

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[2] Such as the American Association on Mental Retardation or the American Public Health Association.

☐ *Using teleconferences*

Another available resource for providing training to staff is through the downlinking (receiving) of special TV broadcasts called teleconferences. A teleconference is a workshop held at an uplinking (broadcast) site sent out over satellite to downlink (receive) sites locally, statewide or nationwide. The reception is on one of two bands, Ku band or C band, the two most common bands for teleconferences. The downlink site registers to receive the transmittal and usually pays a reception fee which can range from $200 to $1,200. The registered downlink site then receives the specific reception information as well as supportive materials supplied by the production site. The reception costs can be shared by agencies and/or by all participants at the receive site. This can make the use of the teleconference approach a very cost-effective method of delivering quality, state-of-the-art information.

Teleconferences addressing generic aging issues and specific aging and developmentally disabled issues are becoming increasingly available from a variety of resources around the country. While the production of a teleconference can be very involved, receiving a teleconference broadcast need be no more difficult than coordinating a training session.

Consider the following to determine if you can provide or receive a teleconference in your area:

- ☐ *access to a downlink site (hospitals, colleges, universities, hotels, government facilities, and some TV stations are places that may have downlink conferencing facilities).*
- ☐ *telephone access close to the viewing area but not within hearing. (For example, directly outside the viewing room.) Most teleconferences provide an 800 (or toll-free) telephone line for interaction with teleconference presenters through question call-in to the production site.*
- ☐ *a knowledgeable person to coordinate the downlink connections and teleconference. This includes but is not limited to arrangements with the viewing site, cost setting, registration to be a downlink site, advertisement of the local teleconference site, registration of participants and preparation for dissemination of the downlink materials provided by the production site and any pertinent local materials. It is easier if these tasks are shared among a few willing workers who work well together.*
- ☐ *a room for viewing the broadcast that can hold the number of expected participants. The ideal would be to have a large screen for all to view, however, TV monitors can be used. If you are using TV monitors make sure there are enough in the room for all participants to be able to see the teleconference. The larger the TV monitor the better viewing opportunity for your participants.*
- ☐ *one or more aging and developmental disabilities "experts" who are available to respond to questions on site, to fill in when there is a technical malfunction, and to provide a "local drawing card" for participants.*
- ☐ *technical consultants available to actually receive the broadcast at the scheduled time.*

If you can access a site that has had successful experiences in receiving teleconferences in the past, the site will take care of the technical aspects. You will then only need to consider the arrangements, usually connected with coordinating the workshop.

Producing a teleconference, though very time-consuming, is a way to share your expertise with others. Consider that a site with downlink capability may also have uplink capability, giving you the ability to teleconference any training you develop to other parts of your state or the country. Transoceanic broadcasts are possible, but become extremely costly because of international fees and difficult to coordinate because of time-zone differences.

Coordinating a teleconference broadcast involves some of the following:

- ***broadcast funding underwriting:*** *A teleconference broadcast can be expensive initially, ranging from $10,000 to $50,000+ depending on the extent of the broadcast. These costs can be shared by agencies and/or charged back to downlink sites. Grants or shared funding arrangements can also be used to defray costs.*
- ***information or expertise you wish to broadcast:*** *Is the information or expertise of sufficient interest to other areas to warrant sites to pay for the reception of your broadcast? Is this the most cost-effective or best method to share this information and/or expertise?*
- ***interest:*** *Is there sufficient interest in your topic to assure a minimum number of downlink sites?*
- ***local technical capability:*** *You should attempt this only if the upinking equipment is available and with an institution that has experience with successful teleconferencing.*
- ***people willing to devote large blocks of time to the coordination of the production:*** *This is a very labor intensive activity and that needs to be considered as a major cost factor. The person or people also need the support of their agencies to be able to devote the needed time.*

Using a teleconference to share and exchange information involves accessing a relatively new technology which offers exciting training possibilities for the future. Take the time to see if this new technology can be a resource for you.

☐ *Setting up staff exchanges*

Another method of cross-training and network building uses a staff exchange program. What is a staff exchange? It is the placement of an individual from one agency temporarily within another agency for the purpose of becoming familiar with the workings of that agency. For example, it could involve placing a person who works in the developmental disabilities network within an aging agency, or placing a person who works in the aging network within a developmental disabilities agency. Staff exchanges have been found to help provide a better understanding of work within and between the two networks and to be of great benefit to the participants as well.

Setting up and managing a staff exchange program can be done with a minimum of cost and coordination. The amount of time staff are involved in the exchange can vary from half-a-day to five days per week. Arrangements, such as scheduling and release time need to be worked out in advance among agency administrators and participating staff. Placements can also be brokered by a third party and included as part of a formal training program. To carry out a staff exchange program, consider the following:

- *set up your institution as the formal sponsor for the exchange program and offer central coordination, placement brokering, and mentoring;*
- *designate a staff exchange program coordinator (who would make the contacts, keep records, write letters, and in general, keep "tabs" on the situation)*
- *develop a prospectus for a staff exchange program that would explicitly spell out the program's goals and objectives, state responsibilities of participating agencies and participating staff, define timeframes and financial obligations, and identify sponsor and co-sponsors*
- *establish a core of mentors who could oversee the placement of the individual participants (they would meet periodically, individually or in participant groups with their supervisors);*
- *solicit agencies willing to participate via letter or interagency meeting;*
- *solicit staff interested in participating in the program (for example, persons who have attended your training sessions, individuals who have participated in cross-training, or members of networks or coordinating groups);*
- *make placement arrangements through the agency administrator (brokering release time for the agency placements, mentoring sessions, in-service credits earned);*
- *maintain records of persons and agencies involved in staff exchange program.*

☐ *Implementing "train-the-trainer" approaches*

There are a number of approaches that can be used for training. Many of these rely on different local resources which can facilitate training. Such resources may consist of *settings, trainers* and *curricular materials.* Experience has shown that most localities can provide adequate settings, but often lack either qualified personnel or the curricular materials. In this section, we have discussed alternative settings in which training can take place and we have provided information on curricular materials. This segment considers how to develop trainers.

The train-the-trainer" approach is another means of providing training and building training expertise. Staff turnover is often a problem in many agencies. Thus, there is a need to repeat inservice courses and workshops on a regular basis. One way of assuring that this can be done is to invest time and effort in developing the training abilities of a number of targeted individuals, or trainers. Many agencies have personnel designated to provide in-service training and through their participation in a specific training program, they can gain the proficiency to become trainers on the topic of aging and developmental disabilities. Creating a cadre of persons who can provide local training on aging and developmental disabilities issues can prove to be a valuable investment.

One approach to implementing a "train-the-trainer" program is to do the following:

- *develop (or have available) a packet of materials that will form the basis for the training; these materials will be used by the trainers to develop and deliver their own training services.*
- *assume that, in most instances, the trainers will have little or no understanding of aging and developmental disabilities issues and approaches, thus the materials should be comprehensive (including text and videos).*
- *develop a strategy to give the trainers the means and experiences to deliver the training packages you have developed.*
- *provide the trainers with intensive training, with you or your own trainers serving as role models for the presentation of the materials and explanation of its content.*
- *make available in-person or telephone consultation so that the trainers can confer and check with you when they are developing and presenting their training sessions.*
- *provide follow-up training sessions to help the trainers get feedback and gain new information.*

These types of approaches should aid in increasing and augmenting expertise in areas that need both inservice and cross-training programs.

☐ *Providing consultation*

Another type of training approach is to provide consultation. Consultation can be offered on the needs of a specific person, on a particular program, or on implementing a training series. Consultation can provide unique opportunities for training. In addition to sharing your particular suggestions about the problems that are presented, you can take the opportunity to offer information in a broader context. Often you can elicit from the audience their perceptions on an issue and provide a "mini-inservice" on the spot.

☐ *Evaluating training*

Measuring effectiveness can be a complex process. Most of the designs that can be used are quite complex and often involve ethical constraints that may pose difficulties for most training programs. Thus, these designs are best left to experts. However, several practical strategies can be employed to approach evaluation in a simplified manner and are well within the capabilities of most agencies. These include measures of:

- satisfaction with the training,

- training process, and
- training impact.

Perhaps the central question to any training program is "Did it work?" For example, "Did your training program on caregiving strategies for adults with Alzheimer's disease help residence staff to work more effectively with a resident suspected of having Alzheimer's disease?" or "Did your workshop on program planning for older people with developmental disabilities really assist staff in developing new and innovative program options?" These are questions of ***program effectiveness***.

By asking simple questions related to satisfaction with the training process, and the effectiveness of the training materials, you can gain insight into the impact of your training program at little expense. This type of evaluation process is referred to as ***impact or outcome evaluation***. It tells you whether things became better or worse as a result of providing the training. This method, however, does not tell you whether your training program *per se* was responsible for the results. Each of these methods, however, can help to give you valuable information. Consider doing the following:

- *measuring satisfaction with training by asking participants for their reactions to the training or, more directly, whether or not they were satisfied with the training. The core question is: if the participants were satisfied with the training, will they use the concepts and techniques in their daily work?*
- *assessing the training process by asking the participants their assessment of the teaching methods and their reactions to the subject matter being taught. Feedback from this type of questioning will yield useful information for trainers on how to improve their teaching methods and improve the material being presented. The core question is: if the participans rate the teaching methods as useful and find the subject matter worthwhile, will they use the concepts and techniques in their daily work?*
- *measuring training effectiveness by asking the participants for their subjective impressions on whether they have noticed changes in their work outcomes as a result of employing the concepts and techniques they have been taught. Additional questioning may yield information on what skills the participants are now using most effectively, which are the most difficult to apply, and whether anything become less effective as a result of using the concepts and techniques.*

One means of collecting evaluation information is with the use of a mailed questionnaire. Such questionnaires are generally short, simple, concise, anonymous and represent a mix of closed and open-ended questions.

- ***Closed-ended questions*** are useful for gathering satisfaction and training process information. (Closed-ended questions may ask the respondent to chose from two or more answer-options by checking a box or circling a number; for example, "*Please rate the handouts in terms of usefulness: (1) very useful, (2) somewhat useful, (3) not useful.*")

- ***Open-ended questions*** are useful in gathering participant perceptions as to use and effectiveness of taught materials. (Open-ended questions begin with a sentence or question and the respondent is asked to write a response; for example: *"How were you able to apply the information on use of senior centers?"*)

Designing a questionnaire is not difficult. It should ask questions about the training and the participants opinions about it. It can be mailed to the participants (or a sample of the participants) at some point after the training. Many participants may not begin to use the newly taught skills immediately, so the questionnaire should be mailed following some interval after the training.

Training at the university level

One of the more vexing problems facing individuals charged with delivering needed services to our nation's citizens with life-long disabilities has to do with the lack of understanding among aging network workers of what constitutes a developmental disability, and among disabilities system workers, of what constitutes aging. Recent inquiries have shown that workers who have such "blended" backgrounds in both aging and developmental disabilities are at a minimum.

This means that workers in both the aging network and in the disabilities network may be ill-prepared to address the combined effects of life-long disability and aging. Today, few university programs have developed training programs in this area so there is a dire need for university personnel who are equipped to provide training. How can university programs address the need for information about aging and developmental disabilities? One way is by acknowledging that:

- the aging of persons with life-long disabilities is a multi-faceted problem,
- part of the problem is that often mental retardation and other related disabilities are not seen in the context of lifespan development or aging, but as childhood disorders and that, consequently, many of the interventions and services are offered in the context of child-oriented approaches,
- most workers in the field of developmental disabilities have been trained to work with childhood issues or the residuals of childhood disability and they are often totally unprepared to address the problems of their ever-aging clientele, and that
- university and continuing education curricula need to contain courses on adult development and aging.

Given the similarities of services in the fields of aging and developmental disabilities, it would seem that university affiliated programs, working in concert with university gerontology and geriatric medicine programs, would be best suited to begin to provide training or re-training for this group of workers.

Setting up training at the university level

Training at the university level can take several forms. There is a need to develop specific courses and have instructors and academic institutions willing to participate. This training can range from presentations in one session of a specific course, to modules within existing courses, to a full-fledged academic course at the undergraduate or graduate level. A helpful way to begin the process is to do the following:

- *design a module on aging and developmental disabilities that can be infused in to existing courses.*
- *identify the academic institutions that may be interested in participating.*
- *identify undergraduate, graduate and certificate courses that are logical vehicles for infusion.*
- *identify instructors who can do the infusion in their courses, or would welcome a guest lecturer.*
- *contact those instructors and give them sufficient time to plan the course infusion.*
- *design pre- and post-test questionnaires that can measure the impact of the materials on the increased knowledge of the students.*
- *build on the knowledge gained from course infusion and design a semester course in aging and developmental disabilities.*
- *include the identified instructor in the development of the curriculum to ensure support and a sense of ownership.*

After you have begun to implement some of these ideas within academic institutions, you may wish to organize a workshop for instructors. This would facilitate refining the curricular and instructional materials that you have been using. Such instructors may be drawn from local community colleges, provider or vendor agencies (both within the aging network and the developmental disabilities system), and from among professionals working within your area.

A number of colleges have developed specific curricula for use in classes on aging, developmental disabilities, social work and the various health sciences. For information on specific course curricula available at the junior college, college or university level, contact the:

- American Association of University Affiliated Programs (8630 Fenton Street, Suite 410, Silver Spring, MD 20910) or the
- Association of Gerontology in Higher Education (1001 Connecticut Avenue, N.W., Suite 410, Washington, DC 20036-5504).

AGING & DEVELOPMENTAL DISABILITIES UAP TRAINING CENTERS

Mailman Center for Child Development
University of Miami School of Medicine
PO Box 016820 - D-820
Miami, FL 33101
305/545-6359

Shriver Center University
Affiliated Program
200 Trapelo Road
Waltham, MA 02254
617/642-0101

Montana University Affiliated Program
33 Corbin Hall
University of Montana
Missoula, MT 59812
406/243-5467

Waisman Center UAP
University of Wisconsin
1500 Highland Avenue
Madison, WI 53705-2280
608/263-4897

The University of Georgia UAP
850 College Station Road
Athens, GA 30610
404/542-3960

Institute for the Study of
Developmental Disabilities
Indiana University
2853 East Tenth Street
Bloomington, IN 46405
812/855-6508

University Affiliated Program for
Developmental Disabilities
University of Missouri at
Kansas City
Institute for Human Development
2220 Holmes Street
Kansas City, MO 64108
816/276-1770

University Affiliated Program for
Developmental Disabilities
University of Rochester Medical
Center
Box 671
601 Elmwood Avenue
Rochester, NY 14642
716/275-2986

Training resources

There are a number of resources that you can tap to aid in training staff and volunteers to better understand aging and developmental disabilities; several are identified in the table on pages 101-105. For others, you can check within your state or locality as to what is available. Such local resources can include:

- training curricula on developmental disabilities available through the state mental retardation/developmental disabilities agencies statewide or local staff development units.
- training curricula on aging and developmental disabilities available through mental retardation/developmental disabilities aging services specialists.[3]

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[3] For a listing of the state aging specialists employed by state mental retardation & developmental disabilities agencies check the most recent issue of the *Aging/MR IG Newsletter*, available from the American Association on Mental Retardation, 1719 Kalorama Road, N.W., Washington, DC 20009-2683 or the Gerontological Society of America, 1411 K Street, N.W., Suite 300, Washington, DC 20005.

- training programs available through the ADD funded University Affiliated Program - Aging and Developmental Disabilities Training Centers (see box on page 99).[4]
- training available through the network of area agencies on aging.[5]
- training and resources available from the network of Geriatric Education Centers and the network of centers on aging, institutes on aging, gerontology centers, and the like.[6]
- training available from local branches of the Alzheimer's Association.[7]
- training information available in the *Aging/MR IG Newsletter* published by the Special Interest Group in Aging of the American Association on Mental Retardation/Special Interest Group in Mental Retardation & Developmental Disabilities of the Gerontological Society of America.[8]
- resource materials from the National Institute on Aging (e.g., *Age Pages*)[9], the U.S. Administration on Aging[10], and various Councils[11].

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[4] Information on the location of other University Affiliated Programs (UAPs) that may have a component on aging can be obtained from the American Association of University Affiliated Programs in Developmental Disabilities, 8630 Fenton Street, Suite 410, Silver Spring, MD 20910; telephone 301/588-8252.

[5] Information on training generally available from area agencies on aging can be obtained from the National Association of Area Agencies on Aging, 1112 16th Street, N.W., Suite 100, Washington, DC 200364; telephone 202/296-8130.

[6] Contact the Health Resources and Services Administration of the Public Health Service (Geriatric Education Centers Program, Associated Health Professions Branch, Division of Associated and Dental Health Professions, Rockville, MD 20857; telephone 301/443-6887) for information on the local of the GECs. For information on centers on aging contact the Association for Gerontology in Higher Education (1001 Connecticut Avenue, N.W., Suite 410, Washington, DC 20036-5504; telephone 202/429-9277).

[7] Information on local chapters can be obtained from the Alzheimer's Disease and Related Disorders Association, Inc., 70 East Lake Street, Chicago, IL 60601-5997; telephone 800/621-0379 or 312/853-3060.

[8] Contact the AAMR, 1719 Kalorama Road, N.W., Washington, DC 20009 (telephone 202/387-1968) or GSA, 1411 K Street, N.W., Suite 300, Washington, DC 20005 (telephone 202/842-1275).

[9] For copies of *Age Pages* and other NIA materials, contact NIA Public Information Office, Federal Building, 6th Floor, Bethesda, MD 20892.

[10] For information on available publications and materials contact the Administration on Aging, 330 Independence Avenue, S.W., Washington, DC 20201 (telephone 202/619-0011).

[11] Materials are available from the National Council on the Aging (409 Third Street, S.W., Washington, DC 20024; telephone 202/479-1200); National Advisory Council on Aging (Information Officer, Trebla Bldg., 473 Alberta Str., 3rd Fl., Ottawa, ON K1A 0K9 Canada); Australian Council on the Aging (449 Swanston Street, Melbourne, Victoria, 3000 Australia).

Education and Training Resources

Name of Resource	Available From & Contents
Training Manuals	
Aging and Developmental Disabilities: North Dakota Statewide Developmental Disabilities Staff Training Program (1991) Author: D. Vassiliou	Minot State University, The North Dakota Center for Disabilities University Affiliated Program (500 University Avenue West, Minot, ND 58702-5002; telephone 701/857-3580; fax 701/839-6933) *Contents:* 184 pp. *Modules:* Population overview; Philosophical considerations; Health promotion; Mental health issues; Informal support systems; Aging and retirement; Death and dying; Legal rights; Abuse, neglect and exploitation; Case management; Developmental disabilities in North Dakota; Aging services in North Dakota; How to integrate older persons with developmental disabilities *Format:* Learning objectives, narrative, and end of lesson exercises
Serving the Underserved: Caring for People Who are Both Old and Mentally Retarded - A Handbook for Caregivers (1989) Authors: M. Howe, D. Gavin, G. Cabrera & H. Beyer	Exceptional Parent Press (1170 Commonwealth Avenue, Boston, MA 02134; telephone 617/730-5800; fax 617/730-8742) *Contents:* 508 pp. *Modules:* Introductory matter; Assessment by individual discipline; Orientation to interdisciplinary issues; Health and well-being; Living in the community; Ethics; Death and dying *Format:* Textbook; short, concise, informative chapters written by individual contributors
Aging and Developmental Disabilities: A Training Inservice Package (Training Guide and Modules) (1989) Authors: B. Hawkins, S. Ekland & R. Gaetani	Institute for the Study of Developmental Disabilities (Indiana University, 2853 East Tenth Street, Bloomington, IN 47408; telephone 812/855-6508; fax 812/855-9630) *Contents:* approximately 100 pp. *Modules:* Population overview; Philosophical considerations; Medical and health; Community living; Professional services; Service coordination issues *Format* Objectives, individual modules with narrative and resources; trainer's handbook for modules.
Academic Course in Aging and Developmental Disabilities (1990) Authors: R. Machemer & J. Overeynder	Training Program in Aging and Developmental Disabilities (University of Rochester UAP, 601 Elmwood Avenue, Box 657, Rochester, NY 14642; telephone 716/275-2986; fax 716/275-7436) *Contents:*

	43 pp. *Modules:* Introductory matter; Population demographics; Mortality and morbidity; Legal issues Ethical issues; Housing; Service options *Format:* Outline of graduate course content matter and resources.
Refresher Course in Developmental Handicaps (1989) Author: B. Stanton	Queens University at Kingston (Developmental Consulting Program, Suite 301, 80 Queen Street, Kingston, Ontario, Canada K7K 6W7; telephone 613/544-4885) *Contents:* 100 pp. *Modules:* Alzheimer's Disease & Down Syndrome; Enhancing deinstitutionalization efforts; Aging and developmental handicaps; Quality of life *Format:* Concise collection of lectures written by individual contributors
Training Guide for Aging Specialists (1986) Author: P. Kultgen, C. Rinck & D. Pfannenstiel	UMKC Institute for Human Development (University Affiliated Facility for Developmental Disabilities, 2220 Holmes Street, Kansas City, MO 64108, telephone 816/276-1762) *Contents:* 100+ pp. *Modules:* Vision; Hearing; Musculoskeletal system; Cardiovascular system; Gastrointestinal system; Central nervous system; Physical disabilities; Physical appearance and age awareness; Mental disorders; Death and dying; Learning and memory; Dementia of the Alzheimer's type; Work and retirement; Informal support systems; Residential changes. *Format:* Individual chapters of factual material with references and appendices.
Partners Project Handbook: Training Materials in Aging and Developmental Disabilities (1992) Authors: E.F. Ansello [with J. Zink & A. Wells]	University of Maryland Press (c/o Dr. Edward Ansello, MCV-VCU, Virginia Center on Aging, Richmond, VA 23298-0229) *Contents:* 130+ pp. *Modules:* Themes in aging and developmental disabilities; Practical aspects of program implementation; Assessing persons with developmental disabilities; Informal support networks; Drug effects; Accessing community resources; Adult onset handicaps; Overcoming isolation and segregation; Designing recreation programs; Nutrition; Grief, death & dying; Contributions of elders with developmental disabilities.

Textbook and Other Readings

Activities with Developmental Disabled Elderly and Older	Haworth Press (10 Alice Street, Binghamton, NY 13904)

Adults (1991) Author: M. Jean Keller	*Contents:* 156 pp. *Modules:* Activities and adaptation; Developing recreational services; Therapeutic recreation programming; Needs assessments; Art therapy; Arts and crafts; Socialization skills; Integration; Sharing activities; Leisure
Death and Dying: A Guide for Staff Serving Adults with Mental Retardation (1989) Authors: T. Barbera, R. Pitch & M. Howell	Exceptional Child Press *Contents:* 74 pp. Information on issues and practices related to death, dying, grieving and bereavement
I've Seen It All: Lives of Older Persons with Mental Retardation in the Community (1991) Authors: R. Edgerton & M. Gaston	Paul H. Brookes Publishing Company (P.O. Box 10624, Baltimore, MD 21285) *Contents:* 273 pp. Documentation of the life histories of nine adults who lived independently in the community for some 30 years.
Ethical Dilemmas in Caregiving (1989) Authors: M. Howell & R. Pitch	Exceptional Child Press *Contents:* 100 pp. Monograph on conceptual framework, applying ethics to everyday life, and case studies.
Aging and Lifelong Disabilities: Partnership for the Twenty-First Century (1989) Authors: E.F. Ansello & T. Rose	Center on Aging (University of Maryland, Room 1120, Francis Scott Key Hall, College Park, MD 20742-7321) *Contents:* 79 pp. Monograph on conference proceedings; covers background issues, building partnerships, decision-making and public policy, state responses, strategies and recommendations, and public policy implications
Aging and Mental Retardation: Extending the Continuum (1987) Authors: M.M. Seltzer & M.W. Krauss	AAMR (1719 Kalorama Road, N.W., Washington, DC 20009) *Contents:* 187 pp. Monograph includes a review of community and institutional-based day and residential programs currently in operation, and provides specific details of services models that appear to be particularly effective, as well as information on the role and structure of informal support networks.
Aging and Developmental Disabilities: Issues and Approaches (1985) Authors: M.P. Janicki & H. M. Wisniewski	Paul H. Brookes Publishing *Contents:* 427 pp. Text containing 26 chapters, covers biological processes, policy, legal and advocacy considerations, research and planning, various service issues and practices, residential and day programming, family concerns.
Ageing and Mental Handicap (1988)	Croom Helm (UK: 11 New Fetter Lane, London EC4P 4EE); Routledge Chapman and Hall, Inc. (US: 29

Authors: J. Hogg, S. Moss & D. Cooke	West 35th Street, New York, NY 10001); Croom Helm Australia (44-50 Waterloo Road, North Ryde 2113, New South Wales) *Contents:* 411 pp. Text on ageing and mental handicap literature; covers background issues, epidemiology, medical and psychiatric issues, intelligence and adaptive behavior, work and retirement, interventions for changing behavior, residential issues, and informal supports.
Serving the Underserved: Caring for People Who Are Both Old and Mentally Retarded (1989) Authors: M.C. Howell, D.G. Gavin, G.A. Cabrera & H. Beyer	Exceptional Parent Press *Contents:* 508 pp. Text contains 78 chapters, written by a diverse set of professionals, addressing various facets of aging and mental retardation, including assessment, health and well-being, community living, ethics, and death and dying.
Expanding Options for Older Adults with Developmental Disabilities: A Practical Guide to Achieving Community Access (1986). Authors: M. Stroud, E. Sutton & R. Roberts	Paul H. Brookes Publishing *Contents:* 251 pp. Book based upon the experiences of Dr. Roberts and her colleagues with Project ACCESS in Ohio. A companion book, *Activities Handbook and Instructor's Guide*, is also available.
Aging and Developmental Disabilities: Challenges for the 1990s (1991) Editors: M. Janicki & M.M. Seltzer	Special Interest Group on Aging (c/o American Association on Mental Retardation, 1719 Kalorama Road, N.W., Washington, DC 20009) *Contents:* 128 pp. Proceedings of Boston Roundtable on Research Issues and Applications in Aging and Developmental Disabilities; contains four detailed review sections - family issues, community integration, age-related changes, and lifespan development.
Psychotropic Drugs: In Brief (1990) Authors: C. Rinck, W. Rinck & R. Sommi	University of Missouri-Kansas City (Interdisciplinary Training Center on Gerontology and Developmental Disabilities, Institute for Human Development - UAP, 2220 Holmes, Kansas City, MO 64108-2676) *Contents:* 20 pp. Short descriptors of various medications used by older persons with a developmental disability.

Videocassettes

Aging... A Shared Experience (1989)	NYS Office of Mental Retardation & Developmental Disabilities (44 Holland Avenue, Albany, NY 12229) 18 minute VHS format Explores integration concepts. Discussion guide available.
When Persons with Developmental Disabilities Age (1991)	NYS Developmental Disabilities Planning Council (155 Washington Avenue, Albany, NY 12210) 18 minute VHS format Describes a variety of physical and social aging processes. Discussion guide available.

"I Should Know a Lot, I've Been Around So Long:" Stories of People with Mental Retardation Who Have Lived Long Lives (1987)	Shriver Center (200 Trapelo Road, Waltham, MA 02254) 30 minute VHS format from slides Illustrates the lives of a number of older persons with mental retardation.
"Side by Side" (1991)	Oneida County Aging and MRDD Coalition (P.O. Box 4771, Utica, NY 13504) 12 minute VHS format Illustrates experience of organizing a local network group and experiences of senior center and disability agency sharing activities.
"Bridging the Networks: Dignified Alternatives for Aging Persons with Developmental Disabilities" (1991)	Oneida County Aging and MRDD Coalition (P.O. Box 4771, Utica, NY 13504) 2 hour VHS format Copy of national teleconference on aging and developmental disabilities originally telecast on May 9, 1991; includes presentations by experts and telephone question and answer period.
"Life Reminiscence" (1991)	University of Missouri-Kansas City (Interdisciplinary Training Center on Gerontology and Developmental Disabilities, Institute for Human Development - UAP, 2220 Holmes, Kansas City, MO 64108-2676) 26 minute VHS format Reviews similarities and differences among older persons with developmental disabilities from their own perspectives; useful for training in empathy, value-based planning, and skills communications.

Special Journal Issues

Journal of Applied Gerontology Cotten, P.D. & Spirrison, C.L (Special Editors).	SAGE Publications, Inc., 2111 West Hillcrest Drive, Newbury Park, CA 91320. "Issue devoted to elderly persons with mental retardation" (12 articles). 1989 (volume 8, number 2), pp. 149-270.
Mental Retardation Janicki, M.P. (Special Editor).	American Association on Mental Retardation, 1719 Kalorama Road, N.W., Washington, DC 20009-2684. "Symposium on aging" (7 articles). 1988 (volume 26, number 4), pp. 179-216.
Australia and New Zealand Journal of Developmental Disabilities Janicki, M.P. & Hogg, J.H. (Special Editors).	Special Interest Group on Aging, c/o AAMR, 1719 Kalorama Road, N.W., Washington, DC 20009-2684 (or Dr. Trevor Parmenter, Editor, ANZJDD, c/o Unit for Rehabilitation Studies, School of Education, Macquarie University, North Ryde, N.S.W. 2109 Australia). "Special aging issue" (16 articles). 1989 (volume 15, number 4/5), pp. 163-337.
Educational Gerontology Rose, T. & Ansello, E.F. (Special Editors).	Hemisphere Publishing Corp., 1101 Vermont Avenue, N.W., Suite 200, Washington, DC 20005-3521. "Special issue on aging and disabilities" (10 articles). 1988 (volume 15, number 5) pp. 351-469.
Journal of Practical Approaches to Developmental Handicap Brown, R. (Editor)	JPADH, Rehabilitation Studies, 4th Floor, Education Tower, University of Calgary, 2500 University Drive, N.W., Calgary, Alberta T2N 1N4 Canada. "Special issue of articles stemming from International Conference of Aging and Disability" (6 articles). 1988 (volume 12, number 2) pp. 1-32□

Section 9

Developing Programs

Older persons with mental retardation and other developmental disabilities represent a diverse population. Although the largest number are mildly and moderately handicapped, a significant number are also severely and profoundly impaired. The types of impairments that people have and their abilities vary greatly, as do their needs for a variety of services. In some instances intellectual handicap may play a role in determining program need; in other instances, it will be the degree of physical and social abilities. As with developing programs for America's overall older population, the challenge to administrators, planners, service providers, and others is to offer an array of options that can accommodate a variety of needs of those older persons with developmental disabilities.

The future of services to older people is based upon building a service system that listens and responds to the stated needs of the individuals it is designed to aid. This means going beyond traditional models of care and services to ensure that older persons with a developmental disability can each define what they need, get services in manner that makes them part of the greater community, and promotes quality of life well into old age.

Thus, we must begin to challenge the assumptions under which we develop and provide services. Even the basic premise of how we see older persons. The concept of ***successful aging*** provides a useful programmatic underpinning for developing programs for older persons with developmental disabilities. Successful aging is defined in terms of an individual retaining his or her abilities to function as independently as possible into old age. Persons who age successfully are able to remain out of institutions, maintain their autonomy and competence in all their activities of daily living, and continue to engage in productive endeavors of their own choosing.

With younger persons with a developmental disability, the rehabilitative intent is the promotion of skill development to assist that individual to be as independent as possible so that he/she can be a competitive member of society, effectively using social amenities, working, and enjoying the freedom of having his/her own household. With persons in later life, independence remains an important goal; however, it now moderated by another complimentary goal: ***interdependence***, which is realized by fostering social skills that maintain personal independence.[1] Thus, among individuals who are elderly, independence is now no longer stated in terms of vocational competitiveness, but in terms of continued social and personal competence (that is, maintaining activities of daily living -- ADLs -- and avoidance of institutionalization). Program development, if it is to be successful, needs to meld together the concepts of successful aging, interdependence, and independence.

SUCCESSFUL AGING

...the capability of an older person to retain his or her ability to function as independently as possible in old age, by not needing to be institutionalized, by remaining competent in self-care abilities, by remaining physically capable, and by being able to get about by oneself...

In any given locality, program development is a function of public policy. A locality will need to determine which program development approach (program integration; specialty programs; or a blending of these two) it wants to pursue. Experience has shown that no one method can sufficiently address the needs of all older persons with developmental disabilities in a given community (of particular concern is developing services for residents of rural areas[2]). Given this, the questions to be answered include: What are the needs of the community? What are its resources? How can the resources address the needs of older persons with developmental disabilities?

Developing day program options

Developing programs specifically designed to accommodate the needs of older persons with developmental disabilities involves a careful blending of the needs of the individuals, available resources, and planning adjustments related to budgetary considerations. Oftentimes, program needs can be met via existing program models. These can range from drop-in recreation/social centers for persons who are retired or who only work part-time, to home supports, pre-retirement training projects, or social/health model adult day care programs. These programs can be age-specific or multigenerational. The table on page 109 considers different groupings of individuals by need levels and potential alternatives in day and residential services. Modifications, if needed, can be made by adjustments to staffing and programs routines.

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[1] Although the term "interdependence" has been used in many contexts, we would like to credit Dr. Paul Cotten, of the Boswell Retardation Center, Sanatorium, Mississippi, for introducing its use in this context.

[2] See *Aging and Developmental Disabilities in Rural America*, available from National Resource Center for Rural Elderly, University of Missouri-Kansas City, 5100 Rockhill Road, Scofield Hall, Kansas City, MO 64110-2499; telephone 816/235-1024.

Service providers and planners are recognizing that even among the elderly, there is a diversity of need, even among those individuals with late-life disabilities or age-associated impairments. Thus, while they are beginning to respond with community support services, such as home health and respite, most of the aging network services have not sufficiently evolved to accommodate persons with long-term dependency or physical care needs.

The developmental disabilities system, however, does have the capability to continue to provide long-term care services to individuals with severe disabilities.[3] It also has the potential to provide social recreational services to persons minimally impaired when no other alternatives exist. In this vein, providers of services to persons with developmental disabilities can also become community resources to other seniors who need adult day services. Such program options should be considered where there are limited senior services; a reluctance to overwhelm existing services with many older persons with lifelong disabilities -- thus changing the character of those services; or where existing aging network services are of poor quality.

Thus, many disability agencies may set up a specialty program for seniors from their immediate community. The following section describes such programs and offers tips on how to provide for their integration.

☐ *Setting up senior day programs*

In a number of states, agencies that have primarily served persons with mental retardation or other developmental disabilities are now establishing and operating specialty programs open to all seniors who might benefit. Most prominent are the programs designed to provide social model adult day care. Many of these programs were originally day activity programs only for persons with a developmental disability. Now they are also serving other seniors with similar levels of impairment from the immediate community.

Such programs are generally developed when:

- social/health model adult day care programs do not exist or are of questionable quality;

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[3] See *Serving Seniors with Severe Disabilities* (available from the Brookdale Center on Aging, Hunter College, 425 East 25th Street, New York, NY 10010-2590).

PROGRAM OPTIONS

Target Group	Day Options	Residential Options
Individuals with ***mild*** functional impairments who have been fairly independent all of their adult lives and because of age-associated impairments may need special assistance from service agencies (level of impairment equivalent to "disability" as defined in Older Americans Act).	Employment and volunteering. Aging network options include: senior centers, congregate meal sites and some social adult day care. Disability services options include work programs, workshops, senior day programs, retirement-oriented programs.	Generic senior citizen housing, independent living situations, shared housing, community residences, group homes, foster family care, living with family with family supports, board and care homes.
Individuals with ***severe*** functional impairments, who have a need for assistance or special training, and who as they age become more reliant upon a range of special developmental services, and/or aging network services (level of impairment equivalent to "severe disability" as defined in Older Americans Act).	Employment and volunteering. Aging network options include congregate nutrition sites, adult day care (social or medical model), some senior centers. Disability services options include sheltered work, retirement-oriented programs, senior day programs or day treatment programs.	Community residences, group homes, neighborhood ICFs/MR, foster family care, living with family with family supports, some senior housing, board and care homes and with advanced age, some nursing facilities.
Individuals with ***age-associated*** functional impairments, compounded by lifelong disability and "frailty," and who require specialized supportive or long-term care services (level of impairment equivalent to "frail elderly" as defined in Older Americans Act).	Aging network options include adult day care. Health system services options include medical model adult day care, sustained nursing services, and nursing facility services. Disability services options include day activity or habilitation programs, senior day programs, ICF/MR services, and other programs.	Community residences, group homes, neighborhood ICFs/MR, foster family care, personal care homes, nursing facilities for frail elderly, and home health supports.

- integration efforts have not yet begun or have not been successful;
- local resources are limited in terms of operating social/health model adult day care;
- developmental disabilities agencies are well established and have decided to offer senior services as part of their services' array; and
- the disability agencies and area agency on aging have worked out an arrangement for the site to be designed as an adult day care program.

The program content at specialized senior day service programs will vary; however, the common theme is one in which the persons served should be able to decide whether or not to participate and be able to choose from a range of activities offered in a relaxed and comfortable atmosphere. In many ways, the goal of these programs is "bring out the best in people." Community-based facilities should be used whenever possible to allow the seniors to participate in age-appropriate activities in a setting that promotes the greatest degree of autonomy and integration.

Program components should contain a variety of daily activities, including health and sensory awareness features, recreation and physical fitness, skill and alertness enhancing activities, socialization, and individual or group discussions or counseling. To this end:

- health reviews, such as periodic checks of hearing and vision, and (as appropriate) blood pressure and nutrition monitoring should be provided during times devoted to health issues;
- recreation activities should include community trips to museums, zoos, plays and musical productions, as well as in-house activities such as cooking projects and gardening, and creative crafts, hobbies and art projects;
- a broad spectrum of activities should be offered in order to provide choices for the participants;
- recognizing the special needs of the participants, by virtue of their age, the program should also offer "down time," when rests or short naps can be taken as needed or indicated;
- social interactions should be encouraged;
- group discussions and reminiscence sessions can aid in orientation to current events; and
- individual and group counseling that addresses emotional needs as well as practical information on budgeting or community support skills should also be available.

Participants should be able to attend either full or part-time. Admission should be based upon age and needs determined by degree of impairment. Admission screening procedures should be based on medical, psycho/social and current program participation assessments. Trial visits are a good idea prior to acceptance into the program, thus aiding in helping the individual discover whether or not he or she has an interest in being involved in the program. Such visits should also serve to acquaint the interested senior with the program.

Program sites should be actively involved with the aging network. For example, by becoming a nutrition site and by being listed in the local aging services directory; this way drawing in other seniors who may not have a developmental disability.

Program space should be appropriate to the needs of the seniors. Program site areas should be accessible to users with physical handicaps, and should contain sufficient program space, a lounge, bathroom facilities and an area for food preparation.[4] The physical layout of the space should include quiet or private areas where participants can relax without background noise, temperature extremes or bright lighting. Controls for temperature and humidity should be located within the program space, and windows provided for fresh air and visual access to the outside. Bathroom facilities should be barrier free and the layout of the program space should be conducive to ease of movement and autonomy.

☐ *Opening senior day programs to the aging community*

The senior day program option offers an opportunity for providing services to older persons who have functional limitations that are age-associated such as dementia, severe mental degeneration resulting from Alzheimer's disease, or where severe physical limitations require special care to benefit from an existing resource in the community; and provides respite to family members who continue to have the responsibility for them.

When the senior day program offers services to all seniors with similar needs and they involve the participants in activities generally available within the aging network, it serves as an a example of **programmatic integration**. This means that the program, itself, has become integrated into the greater aging network through a number of means, such as:

- being designated an adult day care program site by the area agency on aging;

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[4] A source of meals assistance is the U.S. Department of Agriculture's Adult Daycare Meals Reimbursement Program. Although, congregate meal sites receiving financial aid under Title IIIB of the Older Americans Act are not eligible to receive monies under this program, it can be helpful to operators of other senior day programs where meals are provided. Such programs can receive reimbursement of around $2-3 per day per eligible person (defined as either an elderly or chronically impaired individual) for providing a hot or cold meal and snacks that meet the USDA guidelines. For more information about this program, contact the USDA, Food and Nutrition Service, 3101 Park Center Drive, Alexandria, VA 22302

- having the site designated a congregate meal site under Title III of the Older Americans Act;
- having the seniors who are enrolled in the program participate with other impaired seniors in activities developed by the area agency on aging or one of its local agents; and
- developing the site's program such that a portion of the enrollee's time is spent at other locales, such as another adult day care program, senior center or activity program, or congregate meal site.

Participation in a senior day program can offer a variety of learning opportunities and experiences that can aid the transition to other community senior activity programs. Disability programs tend to be highly structured and focussed on goal-directed activities. In contrast, aging network programs are relatively unstructured, leaving participation and involvement in activities largely to the individual. Thus, another design of programs operated by disability agencies is to offer experiences that help in the transition to retirement type programs in the greater community.

To experience satisfaction and success in making the transition to using community aging network programs, many disability agencies are recognizing that individuals retiring to senior activities need a period of acclimation. This helps relieve the constant structure and prepares them for retirement where volition and self-definition are key to participation. These senior day programs serve as a bridge to community aging network programs.

As localities examine the costs of providing special services to the seniors with impairments in their community, cooperative programming and site sharing will become more attractive. If you, as a service provider, are interested in serving non-developmentally disabled seniors, there are a number of things that you can do.

Consider:

☐ *contacting the area agency on aging and discuss becoming designated as an adult day care site.*

☐ *contacting the operator of the county nutrition program and discuss having your senior day program become a congregate meal site.*

☐ *discuss with your Board of Directors opening up enrollment to other seniors with similar functional deficits and needs.*

☐ *contacting the senior companion project coordinator in your local community and discuss becoming a senior companion program site.*

☐ *discussing with your area agency on aging how you might enter into an agreement to share transportation responsibilities for seniors in your local area.*

☐ *getting listed in the area agency on aging's local resource directory as an adult day care site, disabled seniors assistance service, or other service -- depending upon what you wish to offer.*

- *participating in local senior day activities and fairs where aging network agencies display their wares and promote their services.*
- *participating with the area agency on aging in casefinding efforts of homebound seniors with disabilities who are currently unknown to the local care systems.*

☐ *Developing other day program options*

Day services may also involve work activities or volunteering. Many older persons continue to work beyond traditional retirement age in the jobs they hold; others may retire from full-time employment and seek part-time jobs to occupy time and provide supplemental income. Informal and formal work options can range from continuing or starting work, involvement in a older worker program, volunteering, involvement in other community aging network programs, or specialty retirement or activity programs operated by a community social or disability agency.

This section offers a brief overview of work and volunteer options as well as a basic description of typically available aging network programs. Some tips on how to ensure that disability agency operated programs involve a broader range of seniors are also provided. Readers are referred to *Wit to Win: How to Integrate Older Persons with Developmental Disabilities into Community Aging Programs* for more detailed information on day services options and integration techniques for using aging network programs.[5]

☐ Work options

(Employment programs, such as the Senior Community Employment Services Program, help place income eligible seniors with community and government agencies in part-time positions. This program, under Title V of the Older Americans Act, is directed toward seniors age 55 and older whose incomes are within 125% of poverty level. Other agencies, such as state employment service and vocational rehabilitation agencies also aid in locating full-time or part-time employment.)[6]

- **Advantages**
  - provides money for payment of bills and other expenses
  - eases transition to retirement
  - provides money for discretionary spending
  - provides gainful activity
  - continued involvement with other

- **Disadvantages**
  - may not be available, if agency hasn't a retirement policy or program
  - may come up against the annual allowable earned income limit
  - highly dependent upon local

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[5] Available from the New York State Office for the Aging, Two Empire State Plaza, Albany, NY 12229; telephone 518/486-2727.

[6] For more information on senior employment or work programs, see *Aging in America: Implications for Vocational Rehabilitation and Independent Living* (a report of the 17th Institute on Rehabilitation Issues), October 1990, available from the University of Wisconsin-Stout, Research and Training Center, Stout Vocational Rehabilitation Institute, Menomonie, WI 54751; telephone 715/232-1380.

  persons
- intergenerational socialization opportunities

economy and by changes in (un)employment rates

□ **Volunteering**

(Volunteer activities can range from informal efforts designed to provide community activities or resources to formal programs like Green Thumb, Foster Grandparents, or Senior Companions.[7] [8] For example, as a Senior Companion, an older person whose income is less that 125% of federally defined poverty level can be a volunteer for 20 hours per week, receive a tax free stipend of $2.35/hour, and be enrolled in a purposeful volunteer program.)

• **Advantages**
- enrollment in program that provides outlet for wanting to help
- benefit of socializing and making new friends
- offering something back to the community
- usually supervised program, providing gentle guidance for activities
- continued involvement with community activities
- small income, when Foster Grandparent or Senior Companion

• **Disadvantages**
- requires ability to function independently and exercise judgement
- volunteer programs not available in some communities
- transportation to volunteer sites may be a problem
- not all volunteer supervisors are capable of supervising seniors with disabilities

Finding ways to engage in activities that contribute to productive aging can range from taking advantage of selected activities within a community senior center, occasionally going to nutrition sites, or being enrolled in a more formal daycare program. Within the aging network there are three basic types of congregate community programs. In most cases, one or more of the following types of program sites can be found operating in your community.[9] Ideas about how to aid seniors with a developmental disability in accessing and using these programs are covered in the *Wit to Win,* a companion manual. What follows describes some of the options that could be used for day services for older persons with developmental disabilities.

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[7] For information on locating a Senior Companion Program in your area, contact ACTION, Senior Companion Program, 806 Connecticut Avenue, N.W., M-1008, Washington. DC 20525; telephone 202/634-9349.

[8] See *An Instructor's Guide to Training Volunteers: Companion Programs for Older Persons with Developmental Disabilities and their Non-Disabled Peers*, available from the University of Missouri-Kansas City, Institute for Human Development, 2220 Holmes Street, Kansas City, MO 64108-2676; telephone 816/276-1770.

[9] For a more detailed explanation of these aging network community program models and integration tips, see *Wit to Win: How to Integrate Older Persons with Developmental Disabilities into Community Aging Programs*, available from the New York State Office for the Aging, Two Empire State Plaza, Albany, NY 12223-0001. A number of techniques can be used to broaden inclusion in these programs or other community amenities; see *Casebook of Integration Experiences*, available from the CIPADD Project, NYS OMRDD, 44 Holland Avenue, Albany, NY 12229.

□ **Social adult day care or day services programs**
(these are sites that typically provide daytime care and activities for seniors who are frail and/or require supervision.[10] Activities and programs tend to be individualized to meet the specific needs and abilities of participants. They can serve as respite for families who must provide for their elderly relatives or as a program site for others in need.)

- **Advantages**
  - programming is oriented on the basis of individual need
  - staff have experience with persons who have various disabilities and impairments
  - program participants who are not developmentally disabled share similarities in functional abilities with older persons with a developmental disability.

- **Disadvantages**
  - staff ratios at day care sites are lower than those found in the developmental disabilities network day programs.
  - social adult day care programs may not operate under a fixed set of standards so program quality may vary from site to site.
  - categorical funding for social adult day care programs does not exist; most programs are only supported by their funding source and participant fees.

□ **Senior center sites**
(these are programs that typically offer a slate of weekly activities for seniors often accompanied by a daily, hot lunch time meal.[11] Some sites have TV, game, craft, and other activity rooms where multiple activities occur simultaneously. Depending on the center site, some activities may be directed by paid or volunteer leaders. Participation in activities is voluntary and on a first-come, first-served basis. Senior center site users generally tend to be healthy, active and self-selecting in what they do or don't want to do at the center.)

- **Advantages**
  - provides a "right at home, right in the community" experience
  - offers a diversity of activities
  - environment can be stimulating
  - change to make new friends
  - offers the opportunity to socialize and

- **Disadvantages**
  - staff are not likely to have had experience with older persons with a developmental disability
  - supervision is minimal
  - some activities not of interest
  - environment is relatively

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[10] Social model adult day programs are operated by a variety of social agencies and provide daytime socialization and group activities (respite) for seniors and other persons who are chronically impaired. Medical/adult day health care programs, operated by agencies generally certified by the public health authority, admit seniors with medical care needs who do not need to be in a 24-hour nursing care setting. Psychiatric day care programs, operated by mental health agencies and certified by mental health authorities, serve persons who have emotional problems, mental illness, or dementia. In many states, distinctions among these program models are not evident. For more information, see *Standards and Guidelines for Adult Day Care*, available from the National Council on the Aging, 409 Third Street, S.W., Washington, DC 20024; telephone 202/479-1200. See also *Developing Adult Day Care: An Approach to Maintaining Independence for Impaired Older Persons*, available from the National Council on the Aging.

[11] See *Senior Center Standards and Self-Assessment Workbook: Guidelines for Practice*, available from the National Council on the Aging, 409 Third Street, S.W., Washington, DC 20024; telephone 202/479-1200.

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be part of a daily community group
- may provide a hot nutritious noontime meal at low or no cost
- opportunities for "pull out" activities with other seniors

unstructured
- there is a potential climate for bias and discrimination against participants with a developmental disability

□ **Nutrition sites**

(or congregate meal sites are locations where a hot midday meal is provided in a congregate setting to persons aged 60 and over. Persons under age 60 may be served if they are a spouse or are disabled and live with a person age 60 or older. The setting may be at a day care program, senior center or a community location such as a church, school, town hall or community center, etc. The primary purpose of a nutrition site is to serve the noon time meal to those who wish to participate. Nutrition sites serve as a focal point and meeting place for seniors. Often it is the only available place in the community where seniors can meet. Many sites have activities and programs around the meal.)

- **Advantages**
- sites are found in most communities
- provides a community location for a hot meal in the company of age peers
- social atmosphere provides opportunity to make friends
- site offers opportunity to volunteer; for example, with setting up the tables for the meal or helping with the home delivered meals program if food preparation is done on site

- **Disadvantages**
- most nutrition-only sites are open only a few hours a day
- activity programming at sites may be limited or non-existent
- openness to new participants may be a problem
- expected donation per meal may be a budgetary problem

The retirement option

For older persons in general a number of things can impact decision-making in retirement. One, is the *primary gain* associated with work; that is, the wages or salary received. Upon retirement this is usually substituted by Social Security benefits or a pension. Another, is the *secondary gain* associated with the work place, such as friendships, a place to go, and the personal identity that is defined by one's job. Most persons, when considering what to do upon leaving the workforce, think in terms of what they will do to replace work. This notion of replacement leads to "retiring to." It is easy to "retire from," but "retiring to" is more difficult.

Among persons not prepared for retirement, the social and personal changes associated with retirement can be traumatic when some bridging has not occurred as part of the transition process. This may be particularly true for persons with a lifelong disability, some of whom have become dependent upon their workplace both for discretional monies and social supports. Thus, the precipitous loss of income or change in friends when moving to a new setting can become a problem.

For individuals used to earning money through sheltered workshops or other day programs, this loss of money upon retirement can become a problem. The earned money may have real or symbolic value; however, in either instance its loss is felt and may pose a major impediment to wanting to retire. The lack of a "pension policy" (or any substitution scheme for earned income) can pose problems for agencies working with individuals who are of retirement age. Most individuals with a lifelong disability do not receive earned social security benefits or pensions to use as income in retirement.

Many older workers are reluctant to retire when they are faced with the loss of income. This results in a dilemma: when faced with a desire to stop working and relax but lose income, or continue to work and lose the freedom that may come from retirement, many older workers chose to continue to work. Thus, thought needs to be given to the impact of loss of income upon an individual's retirement and becoming involved in a retirement program.

There is another side to this problem. Involvement in certain group senior activities, such an outing or a trip, may include a nominal fee. Further, even participating in a congregate meal program involves some cost since sites ask for a donation per meal. An older person should have the dignity associated with "paying my own way" since many senior activities are peer-oriented and what one contributes is closely watched by the other seniors. Having money to spend in such situations is important to an older individual's dignity and self-respect.

HELPFUL RESOURCES ON PROGRAM AND ACTIVITY TECHNIQUES

All of Us: Strategies and Activity Ideas for Integrating Older Adults with Developmental Disabilities into Senior Centers *(Available from Kent Client Services, 1225 Lake Drive S.E., Grand Rapids, Michigan 49506; telephone 616/774-0853).*

Working with Developmentally Disabled Older Adults: A Training and Resource Manual *(Available from Southeast Pennsylvania Rehabilitation Center of Elwyn Institutes, Baltimore Pike and Elwyn Road, Elwyn, Pennsylvania 19063).*

Strategies for Seniors with Special Needs: Program Manual and Activity Guides *(Available from the Young Adult Institute, 460 West 34th Street, New York, NY 10001-2382; telephone 212/563-7474).*

Innovative Programming for the Aging and Aged Mentally Retarded/Developmentally Disabled Adult *(Available from Exploration Series Press, P.O. Box 706, Akron, OH 44309).*

Meeting social needs is another area of concern. Helping the older person meet new friends or making it possible for a group of friends to retire together can help make retirement more attractive. Ensuring that the "retiring to" activities are attractive and challenging is important. There are a number of strategies that can be used to minimize social problems associated with retirement for older persons with a developmental disability, including:

- pre-retirement counseling,

- partial retirement (where the individual slowly transitions from work to retirement), and
- increased socialization (through the use of "senior friends" and involvement in social programs).

A "senior friend" or retirement coach can help an older person with a developmental disability acclimate to new settings that offer retirement activities, as well as serve as a bridge to the friends he or she may have left at the work setting. One source of such "senior friends" is the federal ACTION agency's Senior Companion Program (see Section 3).[12]

We would certainly recommend a careful review of what concerns the older person may have about retirement and what strategies will be employed to effect "retiring to." This may mean:

RESOURCES FOR RETIREMENT PLANNING PROGRAMS

Pre-Retirement Assessment and Planning for Older Persons with Mental Retardation. *Available from Boswell Retardation Center, P.O. Box 128, Sanatorium, MS 39112 (telephone 601/849-3321).*

Retirement Planning for Older Persons with Developmental Disabilities. *Available from University of Missouri at Kansas City, Institute for Human Development, 2220 Holmes Street, 3rd Floor, Kansas City, MO 64108-2676 (telephone 816/276-1770).*

Retirement Specialist Program. *Available from St. Louis Association for Retarded Citizens, 1816 Lackland Hill Parkway, Suite 200, St. Louis, MO 63146 (telephone 314/569-2211).*

- reviewing with the person what retirement means to him or her and what he or she wants to do;
- examining potential pension options;
- discussing the retirement options; and/or
- implementing pre-retirement activities that employ visits, partial involvement in new situations, and possibly pairing up with a "buddy" to aid in the social adaptation to a new site.

The box on this page lists several manuals that provide detailed information on setting up pre-retirement training programs.

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[12] Senior Companions are adults age 60 and older, of low income, who are recruited to aid elderly persons who are home-bound as well as adults with developmental disabilities. Companions are given a stipend of $2.35 an hour for a 20 hour work week; in addition, they are entitled to meals and an annual physical examination. Their stipend is not considered income for tax and federal benefit purposes. Many communities have a Senior Companion Program. For information on the location of your local program, contact ACTION, Senior Companion Program, 806 Connecticut Avenue, N.W., M-1008, Washington, DC 20525; telephone 202/634-9349.

Developing family supports

Most older persons with a developmental disability, if still living at home, reside with an elderly parent or parents and experience "aging in place." Such a "two-generation elderly family" often requires special services from both the aging and developmental disabilities networks.

In many communities, disability agencies have developed special outreach efforts to aid such families. In some instances, the disability agencies have developed joint efforts with aging network agencies since, under the Older Americans Act, the state's area agencies on aging have the responsibility for providing a number of family supports. These may include:

- services associated with access (transportation, outreach, and information and referral);
- in-home services (homemaker and home health aide, visiting and telephone reassurance, chore maintenance, and supportive services for families of elderly victims of Alzheimer's disease and neurological and organic brain disorders of the Alzheimer's type); and
- legal assistance.

Following are examples of some of the services funded through or provided by an area agency on aging and some thoughts on how they can be helpful to an older person with a developmental disability or their family:

☐ **Information and referral**
(a service designed to help link a person in need with an agency that provides a special service. Often, older family members need assistance but do not know where to call to receive it. By calling the area agency on aging the necessary information can be obtained and linkage made with appropriate agency. It is helpful if a disability agency that provides senior services is listed in the area agency on aging's information and referral sources book. Call the area agency on aging directly to arrange this.)

☐ **Outreach**
(outreach workers help those who are in poor health, who live in isolated areas, who have low income, or who having special problems getting the services and or information they need. Outreach workers are available in many communities; they staff community focal points, such as nutrition sites, and make home visits where necessary. The assistance of an outreach worker can be obtained by calling the area agency on aging.)

☐ **Transportation**
(often parents of an older person with a developmental disability need assistance with obtaining transportation for themselves or their

son/daughter to go to a medical and other appointment. Local aging agencies often provide volunteer drivers or have a van service that can provide transportation upon request.)

- **Home delivered meals**
  (an alternative program for those seniors who can no longer attend a congregate meal site. Generally, meals are delivered if a senior is frail, disabled and or homebound. Frozen meals ready to reheat are available for weekends and in areas which do not have daily delivery. For elderly parents of an adult with a developmental disability who may find it difficult to leave their home, such a service may be beneficial. Contact the area agency on aging for information about the availability of home delivered meals.)

- **Legal services**
  (designed to improve the availability of legal services to elderly persons, such services include representation on matters affecting rights, entitlements, benefits, and other matters directly affecting the senior's general welfare and independence. Legal services are provided by the area agency on aging often via a subcontract with a community legal aid agency. Referrals to private lawyers are made when appropriate. Legal aid workers, while not often well acquainted with the special legal needs of older parents of an adult with a developmental disability, nevertheless might be a resource for general legal concerns. Arrangements can be made with the state's protection and advocacy system to offer training, technical assistance, or other tie-ins to local legal aid staff on issues pertinent to families with an adult member with a developmental disability.)

- **Respite**[13]
  (many area agencies on aging provide a respite program that allows caregivers of older family members to prearrange for care when a vacation or necessary absence from home is planned. If the adult member with a developmental disability qualifies for such a respite placement, this service can be most beneficial to the parents.)

- **Alzheimer's disease support groups**
  (in some instance, either one of the parents or the older adult with a developmental disability may be showing early signs of Alzheimer's disease. Some area agencies on aging provide assistance to support groups for caregivers, as well as offer individual counseling and resource materials to help families with a member with Alzheimer's disease. For

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[13] A good reference on starting a respite program is *How to Start a Respite Service for People with Alzheimer's and Their Families: A Guide for Community-based Organizations*, available from the Brookdale Center on Aging of Hunter College, 425 East 25th Street, New York, NY 10011. See also *Respite Guide: Running a Respite Care Program in the 1990's*, available from the New York State Office for the Aging, Two Empire State Plaza, Albany, NY 12223.

an older person with Alzheimer disease, access to such support groups may often make the difference between continuing to be able to live at home or having to be admitted to an institution.)

The best source of information about what types of family supports may be available in your community is the area agency on aging (AAA). Generally, the AAAs are listed in the telephone directory in the local government listings or in the yellow pages under senior or social services. Most area agencies on aging also publish a directory of services for seniors that is available to the public; such a directory can be helpful in locating the appropriate family supports.

Developing housing options

There are a number of community housing options that are useful to consider. These may be excellent opportunities for older individuals with a developmental disability, who functionally may have the same abilities or limitations as other elderly individuals needing special housing. In some instances, age along with income and functional level (but not categorical disability) are the criteria used to determine eligibility. In other instances age alone may be the factor in determining appropriateness.

We present these so that development personnel may consider how to expand the available community housing options for older persons with developmental disabilities, in particular those whose life-long disability has not been a major impediment to independent functioning.

What follows is a description of the housing options for older persons with a developmental disability. Each of the options is presented in terms of the advantages and disadvantages of using the option for an older person with a developmental disability -- other advantages and disadvantages may become evident, depending upon local conditions. Not all advantages/disadvantages will apply equally and are offered simply to stimulate ideas. The options include a range of community living arrangements and other like programs. They may be known by different terms in your state or area, but will share common characteristics. Medicaid reimbursed ICFs-MR are included because many states use this funding scheme to underwrite small community residences. Besides several community residential options (including supportive apartments and family care/personal care homes generally provided by disability agencies), typical senior housing options included are shared housing, home supports, senior citizens housing, ECHO units, and home equity conversions.[14] We also discuss NORCs, a new phenomenon that should be considered when developing any of the above housing models.

- **Community residences**
  (any of the group living residences, in neighborhood settings, offering supervision, services, board and care.)

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[14] See *Housing Options for Older Americans*, available from the American Association of Retired Persons, Housing Program, 1909 K Street, N.W., Washington, DC 20049.

- **Advantages**
- continued stay in home-like setting
- stable financing
- use of Medicaid personal care for persons with special needs
- adaptability of program due to flexible regulations
- better community medical care tie-in
- flexibility of day program

- **Disadvantages**
- problems with physical barriers when "aging in place"
- need to supplement health/nursing services
- cumbersome rate appeal process-problems with day coverage when residents retire
- need for staff training in aging
- increased need for in-house programming

□ Intermediate Care Facilities for Persons with Mental Retardation (ICFs-MR)

(a small neighborhood group living residence, offering supervision and special services; uses Medicaid funding)

- **Advantages**
- stable financing
- available health/nursing care
- building usually more adaptable
- more professional/clinical staff
- per diem to cover increased cost

- **Disadvantages**
- problems with surveyors who question the continued benefit of program for aging-related service impairments
- some loss of "home-like" atmosphere with medical focus
- medical, not retirement focus
- problems with day coverage when residents retire
- funding limits due to Medicaid screens
- active treatment requirement requires creative approach to goal planning

□ Supportive apartments

(individual or small group living in apartments where seniors live independently -- but may receive periodic visits from a staff person)

- **Advantages**
- normalizing environment
- easy access to local community amenities
- maintaining social network
- greater autonomy
- eligible for in-home aging services
- may be Waiver eligible

- **Disadvantages**
- lack of easy access to medical care
- need to move when become impaired
- frailty leads to restricted mobility
- not a reality for many individuals who function with few self-care or independence capacity skills

□ Foster family care

(living with a surrogate family in the family's home; board and care provided)

- **Advantages**
- grandparent/family model
- long term arrangement
- high community integration potential

- **Disadvantages**
- family caregiver turnover due to aging
- physical barriers in "aging in place"

- availability of Medicaid funded personal care tie-in
- availability of monies for home modifications

situations
- potential isolation from peers
- less easy medical care access

□ Supports to living at home

(supports to older person and family in family home)

- **Advantages**
- remaining with family
- access to family/community physician
- retirement possible
- available in-home supports to elderly
- out-of-home respite tie-in

- **Disadvantages**
- burden on family, specially to elderly parents
- need to tie-in day care for respite
- sometimes not known to system
- support services need to be brokered

□ Shared housing

(group living residences for older adults who share household responsibilities and living expenses; usually no live-in supervision is provided)[15]

- **Advantages**
- normalized living with other seniors
- similar to group homes, but without staff
- does not require site selection
- operated by not-for-profit groups
- relatively inexpensive to operate

- **Disadvantages**
- untried for seniors with developmental disabilities
- limited to seniors with high-independence capacity and skills
- difficulty in finding housemate matches
- zoning barriers may be a problem
- need agency to provide oversight and supports

□ Congregate housing

(publicly operated congregate housing for locality's senior citizens; independent living expectations with some on-site supports provided; congregate housing provides for some 5 to 10 percent of the nation's seniors.)[16]

- **Advantages**
- eligible by age and residency
- living with age peers
- some support services on premises
- physically accessible housing
- two meals per day provided

- **Disadvantages**
- competition with other elderly for scarce units
- may need own transportation
- variable housing quality (depending upon town)
- need to provide supports

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[15] See *Housing Options Sourcebook for Older New Yorkers*, available from New York State Office for the Aging, Two Empire State Plaza, Albany, NY 12223-0001.

[16] The Cranston-Gonzalez National Affordable Housing Act (P.L. 101-625) contains major revisions to the Congregate Housing Services Program (CHSP). For more information, contact US Department of Housing and Urban Development, Elderly and Handicapped People Division, 451 7th Street, S.W., Washington, DC. 20410; telephone 202/708-3291.

▫ **Accessory apartments/units**
(accessory apartments built into family home or free-standing units placed on property adjacent to family home – ECHO units)[17]

- **Advantages**
- independent living near relative
- can live with housemates
- relatively economical to live in
- no regulatory constraints
- eligible for in-home aging services

- **Disadvantages**
- not permitted in every community
- removal requirement - loss of equity
- no "program" support monies
- need to tie-in to day services
- possible loss of residence when family moves or parents die or themselves become frail

▫ **Home equity conversion**
(conversion of assets of high-equity homes by homeowner to provide monthly support funds for living in home)[18]

- **Advantages**
- older disabled adult can be co-owner
- continued living in own home
- regular monies to live on
- can be used to support a shared housing unit
- guaranteed security for set time

- **Disadvantages**
- loss of home when equity runs out of home
- may need agency tie-in for supports
- outside help for home maintenance
- inaccessibility of amenities if suburban/rural
- obtaining equity mortgage dependent upon location and housing market

▫ **Naturally occurring residential communities**
(or NORCs as they have come to be known, are places not originally planned or intended as communities for older people, but where at least half of the residents are now age 60 or older. Such communities can consist of a single building, a development, a entire neighborhood, or even a small town or resort community. They are formed either by older people who have remained after younger people have moved away or by older people moving in after retirement. Gerontologists estimate that about one in four older Americans live in this type of community and expect the number to grow over the next twenty years.)

- **Advantages**
- some social services available
- can prevent early institutionalization
- living in community and neighborhood setting
- friendships and socialization
- clubs and activity groups

- **Disadvantages**
- means living with mostly seniors
- informal services
- many communities not providing special services
- no special funding available

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[17] See *Your Home: Your Choice (A Workbook for Older People and their Families)*, available from the American Association of Retired Persons, Housing Program, 1909 K Street, N.W., Washington, DC 20049.

[18] One source of information on home equity conversion is the National Center for Home Equity Conversion, Suite 300, 1210 East College Drive, Marshall, MN 56258. See also, *Home Equity Conversion*, available from the New York State Office for the Aging, Agency Building Two, Empire State Plaza, Albany, NY 12223-0001.

Adapting physical environments

The design of physical environments is important to integration and programming. If done incorrectly, it can prevent many seniors from using a facility or program. Whether designing a new senior program or aiding in the integration of an existing one, this is an area in which the developmental disabilities network has much expertise and can act as a resource to the aging network, thus ultimately increasing the options for all seniors.

We live in physical environments that are designed for use by the average size able-bodied person. To best use our environment, a person needs to be free of impairments in ambulation, hearing or vision. To be able to travel to sites or enter buildings, a person needs be able to move about without the assistance of adaptive devices or be able to use adaptive devices competently when conditions permit. Unfortunately, notwithstanding recent laws (in particular, the Americans with Disabilities Act) to assure access to buildings, most are still full of physical barriers and will remain so for a number of years to come. As our population continues to age, the physical environment will become increasingly difficult to use by seniors if accessibility is not made a priority in many communities.[19]

A poorly designed physical environment can prevent a person from entering a building or areas where program activities occur. It can also prevent or discourage communication as well as discourage independent movement throughout the building's various areas. Often this can be so subtle that seniors using the environment may not be aware as to why they are uncomfortable in the environment. Thus, they may tend to avoid using the environment without being (or staff members being) aware of the reason.

In integrating seniors with developmental disabilities into an already existing program, you may not be able to control the physical environment. However, you can and should select potential program participants according to their ability to use the already existing environment. You should also work to aid the sites to make their space accessible, both physically and psychologically. Integration attempts can be unsuccessful if you have not considered the impact of the environment on the individuals you are attempting to integrate. The more you are aware of the hidden barriers, the greater the likelihood that the individuals you are helping will experience in using the sites.

Once you have developed a positive working relationship with the program administration and staff, you can use your environmental awareness as a resource for the senior program. You may be able to use your level of awareness and expertise through suggestions of inexpensive or cost-free modifications that can be made to improve the program environment for all seniors participating. However, these suggestions are best held until you are comfortable that program staff and administrators can accept the suggestions in a spirit of interagency cooperation (and not criticism).

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[19] A good reference for adapting a home is *The Do-able Renewable Home; Making Your Home Fit Your Needs*, published by the American Association of Retired Persons, 1909 K Street, N.W., Washington, DC, 20049.

☐ *What to consider during physical site selection*

There are a number of considerations when selecting physical sites for senior programs; these include:

- ***are people able to enter the building and program areas independently?*** The site should have at least one accessible public entrance; parking spaces designated "handicap" should be located close to the entrance; appropriate signage should be present indicating "handicap" parking, as well as accessible entrance(s).
- ***once inside the building, are all the areas you plan to use for programs accessible to all potential program participants?*** Are hallways barrier free and is there unencumbered movement throughout all rooms?
- ***is at least one of the bathrooms conveniently located to program areas and accessible for persons with physical limitations?*** Can persons with mobility impairments get in the bathroom; are there grab bars for independent transfer in the toilet area, is at least one sink reachable; are there usable faucets, reachable soap dispensers and reachable towels; can the door handles and locking mechanisms be used by persons with poor grasping abilities?
- ***are ceiling, windows and wall materials in program areas sound absorbent so that background noises do not pose problems?*** If not, can carpeting, curtains and plants be safely added to the area to cut down on echoing sounds and background noises? Consideration of noise is important because one in four seniors over age 65 has a hearing impairment that is severe enough to get in the way of communication.
- ***is the lighting adequate in hallways?*** Lighting in hallways should make the area easily visible and safe for use; there should not be dark "danger" areas and floors should be free of glare so as not to create shadow effects causing difficulty in mobility.
- ***is the lighting adequate in program areas?*** Lighting should be appropriate for the activities scheduled for those areas, such as close up area lighting for reading or fine motor activities. Providing sufficient glare-free lighting for seniors is extremely important as many seniors will have some form of visual impairment or visual changes.

- ***are color contrasts between floors and walls sufficiently pronounced to provide cues that prevent walking into the walls.*** Are doorway frames painted in contrasting colors so that doors are clearly visible? [As people age distinguishing shades of colors, especially blues and greens, become more difficult due to the yellowing of lenses of the eye.]
- ***are door levers easy to use?*** Does the weight or mounting of doors make opening doors throughout the building difficult; are handles adapted for persons with grasping impairments?
- ***does the lack of awareness and attitude of program staff toward physical barriers create additional problems in the program site?*** Have younger age staff been given experiential training in "living with a disability"?

☐ ***Removing physical barriers***

Oftentimes, reducing physical barriers is a matter of changing attitudes and increasing awareness of the environment. There are a number of inexpensive or cost-free things that can make the experience a successful integration experience.

Consider:

- ☐ *removing furniture or objects placed in walking areas so that the areas are accessible and also safer for walking;*
- ☐ *reducing background noises by turning off radios and TVs during activities when no one is using them; and*
- ☐ *making sure when painting areas to use contrasting colors from the floors and accenting doorways (the exception to this is if wandering off is a problem in a program area; by painting doors the same color as the walls, wandering activity is reduced).*

A last word... running demonstrations

It is useful to start any program initiative with one or more demonstrations. This is true regardless of the type of effort involved, be it targeted integration or the development of a new housing, day services, or support services program model. Demonstrations are useful because they let you test out what you may want to develop on a greater scale under differing sets of conditions, yet remain free of long-term commitments that could compromise your efforts.

The first step in a demonstration effort is to define what you want to find out. You may wish to determine:

- if a certain program model is feasible either from a program or cost perspective;
- that what has worked in some other area will work in the target

area; or

- which of a number of alternative recommendations on implementing a program you want to try under varying conditions.

Once you identify your intent, decide whether you wish to vary funding, staffing patterns, rules or regulations, catchment areas, clientele, or other factors as your test conditions. Although you may not purposely vary a number of conditions, certain key factors, like "doability" and cost should be major considerations. Both of these issues will come up as questions by the agencies that will be providing you with funding or the approval to proceed. Demonstrations are also useful for seeding a new program model that you know will work, but need extra time to phase in.

When developing demonstrations, consider:

- *structuring your demonstration so as to test out the program initiative in terms of cost, programmatic factors, personnel, consumer acceptance, and the like.*
- *providing the demonstration with appropriate and adequate supports, such as technical assistance, local political support, consumer awareness, and financial stability.*
- *providing technical assistance to the demonstration site personnel and others involved or affected by the demonstration.*
- *involving key personnel in inservice and networking opportunities with other like demonstration site personnel.*
- *providing, as warranted, appropriate publicity to help the demonstrations draw clientele and gain community acceptance.*
- *evaluating the impact of the demonstration as to its effect on consumers, effectiveness in addressing its goals, and its cost-effectiveness.*
- *using the demonstration experiences to test alternative means of providing the services (or undertaking the activity), financing or fiscal administration, personnel, locational influences, and the site-specific situational factors.*
- *watching for key personnel at the demonstration sites who are the "sparks" that make them work and who could be asked to speak on behalf of the demonstration efforts at conferences, hearings, and meetings.* ☐

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TABLE 1a

DEMONSTRATION PROJECTS - FIRST SERIES

County Information				
County Name	Erie	Monroe	Madison	Cattaraugus
Population	991,748	715,429	66,068	86,449
N County Pop 60+	192,006	118,107	10,091	15,677
% County Pop, 60+	19.4%	16.5%	15.3%	18.1%
N County Pop Known DD	115	97	17	42
N County Pop Est. DD	760	468	40	62
County Character	Urban	Urban	Rural	Rural
Aging Network Programs				
# Sr. center programs	24	19	7	25
# Nutrition sites	67	20	12	15
# Adult day care sites	1	1	2	2
Demonstration Projects				
Agency with contract	People, Inc	Rochester Regional Council/Aging	Madison Co Office for Aging	Cattaraugus Co Department for Aging
Project funding (per year)	$50,000	$38,000	$20,000	$38,000
Project functions				
casefinding?	yes	yes	yes	yes
sr. companions used?	yes	no	yes	yes
integrate day care?	no	no	yes	yes
integrate sr centers?	yes	yes	no	no
integrate meal sites?	no	yes	yes	no
staff-sharing?	yes	no	no	no
training others	?yes	yes	yes	yes
# persons served with developmental disabilities	15	17	7	25

DD = persons with developmental disabilities

Population data from *Strategies and Barriers*, current as of 1987.

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TABLE 1b

DEMONSTRATION PROJECTS - SECOND SERIES

County Information						
County Name	Queens	Queens	Erie	Chautauqua	Steuben	Sullivan
Population						
N County Pop. 60+	408,070	408,070	192,006	29,721	18,445	13,980
% County Pop. 60+	21.3%	21.3%	19.4%	20.4%	19.0%	20.6%
N County Pop. Known DD	90	90	115	94	43	140
N County Pop. Est. DD	1616	1616	760	118	73	55
County Character	Metropolitan	Metropolitan	Urban	Rural	Rural	Rural
Aging Network Programs						
# Sr. center programs	95	95	43	6	2	0
# Nutrition sites	72	72	57	16	8	13
# Adult day care sites	4	4	5	2	4	0
Demonstration Projects						
Agency with contract	ACRMD, Inc.	UCP/ Queens	People, Inc.	Chautauqua Office f/t Aging	Pathways, Inc.	Sullivan Co. ARC
Project funding (per year)	$73,000	$91,000	$120,000	$71,000	$55,909	$326,380 (1st yr with start-up)
Project functions						
senior companions used?	no	yes	no	no	no	yes
integrated program?	no	no	no	yes	yes	yes
program a daycare site?	no	no	no	yes	yes	no
# persons served with developmental disabilities	20	31	11	3	15	98

TABLE 1c

DEMONSTRATION PROJECTS - THIRD SERIES

County Information						
County Name	Queens	Brooklyn	Brooklyn	Brooklyn	Staten Island	Staten Island
Population						
N County Pop 60+	408,070	396,806	396,806	396,806	55,065	55,065
% County Pop, 60+	21.3%	17.7%	17.7%	17.7%	14.8%	14.8%
N County Pop Known DD	90	70	70	70	71	71
N County Pop Est DD	1616	1571	1571	1571	218	218
County Character	Metropolitan	Metropolitan	Metropolitan	Metropolitan	Urban	Urban
Aging Network Programs						
# Senior center programs	95	121	121	121	28	28
# Nutrition sites	72	103	103	103	17	17
# Adult day care sites	4	2	2	2	0	0
Demonstration Projects						
Agency with contract	UCP/ Queens	Builders for Family & Youth/Diocese of Brooklyn	Jewish Assoc for Services to Aging	Park Slope Day Care	A Very Special Place	Community Agency for Sr Citizens
Project funding (per year)	$50,000	$30,000	$25,000	$60,000	$50,000	$25,000
Project functions						
case-finding?	yes	yes	yes	yes	yes	yes
senior companions used?	yes	no	no	no	no	no
integrated program?	no	yes	yes	yes	yes	yes
training others	yes	yes	no	no	yes	yes
# persons served with developmental disabilities?	10	19	20	*	10	10

TABLE 2A

PROVISIONAL ESTIMATES OF THE U.S. POPULATION FOR SELECTED AGE GROUPS, BY STATE (JULY 1, 1989)

	(Numbers in thousands)		(Percentage)				
State	**All Ages**	**55+**	**60+**	**65+**	**55+**	**60+**	**65+**
U.S. total	248,239	52,577	41,851	30,984	21.2	16.9	12.5
Alabama	4,118	875	697	523	21.2	16.9	12.7
Alaska	527	52	35	22	9.9	6.7	4.1
Arizona	3,556	770	624	464	21.7	17.5	13.1
Arkansas	2,406	566	462	356	23.5	19.2	14.8
California	29,063	5,438	4,245	3,071	18.7	14.4	10.6
Colorado	3,317	561	438	324	16.9	13.2	9.8
Connecticut	3,239	755	600	441	23.5	18.5	13.6
Delaware	673	144	112	79	21.3	16.6	11.8
District of Columbia	604	129	103	76	21.4	17.0	12.5
Florida	12,671	3,661	3,027	2,277	28.9	23.9	18.0
Georgia	6,436	1,164	900	653	18.1	14.0	10.1
Hawaii	1,112	219	171	119	19.7	15.4	10.7
Idaho	1,014	188	154	121	18.6	15.2	11.9
Illinois	11,658	2,467	1,954	1,437	21.2	16.8	12.3
Indiana	5.593	1,178	936	694	21.1	16.7	12.4
Iowa	2,840	674	553	428	23.7	19.5	15.1
Kansas	2,513	559	452	343	22.2	18.0	13.7
Kentucky	3,72	785	627	472	21.1	16.8	12.7
Louisiana	4,382	814	649	487	18.6	14.8	11.1
Maine	1,222	273	219	164	22.3	17.9	13.4
Maryland	4,694	925	715	509	19.7	15.2	10.8
Massachusetts	5,913	1,359	1,093	813	23.0	18.5	13.8
Michigan	9,273	1,895	1,501	1,100	20.4	16.2	11.9
Minnesota	4,353	902	725	549	20.7	17.6	12.6
Mississippi	2,621	535	430	326	20.4	16.4	12.4
Missouri	5,159	1,187	954	719	23.0	18.5	13.9
Montana	806	169	137	106	21.0	17.0	13.2
Nebraska	1,611	363	294	224	22.5	18.2	13.9
Nevada	1,111	213	165	121	19.2	14.9	10.9
New Hampshire	1,107	218	172	126	19.6	15.5	11.4
New Jersey	7,736	1,802	1,418	1,021	23.3	18.3	13.2
New Mexico	1,528	281	220	161	18.4	14.4	10.5
New York	17,950	4,094	3,225	2,341	22.8	18.0	13.0
North Carolina	6,571	1,387	1,092	798	21.1	16.6	12.1
North Dakota	660	143	117	92	21.6	17.8	13.9
Ohio	10,907	2,399	1,906	1,399	22.0	17.5	12.8
Oklahoma	3,224	688	556	428	21.4	17.2	13.3
Oregon	2,820	597	495	392	21.2	17.6	13.9
Pennsylvania	12,040	3,025	2,450	1,819	26.1	20.3	15.1
Rhode Island	998	242	198	148	24.3	19.8	14.8
South Carolina	3,512	677	532	390	19.3	15.1	11.1
South Dakota	715	165	134	103	23.0	18.7	14.4
Tennessee	4,940	1,056	837	625	21.4	17.0	12.6
Texas	16,991	2,971	2,324	1,714	17.5	13.7	10.1
Utah	1,707	240	192	146	14.0	11.2	8.6
Vermont	567	112	90	68	19.8	15.8	11.9
Virginia	6,098	1,176	912	657	19.3	15.0	10.8
Washington	4,761	912	737	567	19.2	15.5	11.9
West Virginia	1,857	435	356	272	23.5	19.2	14.6
Wisconsin	4,867	1,066	860	652	21.9	17.7	13.4
Wyoming	475	69	57	46	14.6	12.0	9.8

SOURCE OF DATA: U.S. Bureau of the Census, Current Population Reports, Series P-25 (Administration on Aging).

TABLE 2b

NUMBER AND PERCENT OF PERSONS 60+, BY STATE: 1989 AND PROJECTIONS FOR 2000 AND 2010

(Numbers in thousands)

State	1989		2000		2010	
	Number	Percent of all ages	Number	Percent of all ages	Number	Percent of all ages
U.S., total	41,851	16.9	45,582	17.0	55,540	19.7
Alabama	697	16.9	757	17.4	906	20.3
Alaska	35	6.7	44	7.3	67	10.0
Arizona	624	17.5	838	18.1	1,172	21.2
Arkansas	462	19.2	489	19.5	583	22.8
California	4,245	14.6	5,084	15.0	6,717	17.6
Colorado	438	13.2	496	14.5	640	18.9
Connecticut	600	18.5	620	18.1	720	20.5
Delaware	112	16.6	131	16.4	168	18.0
District of Columbia	103	17.0	107	17.9	122	19.5
Florida	3,027	23.9	3,960	24.3	5,253	26.7
Georgia	900	14.0	1,115	13.9	1,540	16.4
Hawaii	171	15.4	226	16.6	309	19.4
Idaho	154	15.2	156	15.5	191	19.4
Illinois	1,954	16.8	1,942	16.6	2,157	18.6
Indiana	936	16.7	949	16.7	1,074	19.0
Iowa	553	19.5	512	20.1	534	23.7
Kansas	452	18.0	460	18.2	526	21.1
Kentucky	627	16.8	644	17.5	743	20.9
Louisiana	649	14.8	663	16.0	763	19.7
Maine	219	17.9	227	16.9	273	19.1
Maryland	715	15.2	837	14.9	1,097	17.0
Massachusetts	1,093	18.5	1,089	17.7	1,251	19.4
Michigan	1,501	16.2	1,492	15.9	1,686	18.1
Minnesota	725	16.7	760	16.6	905	19.5
Mississippi	430	16.4	462	16.7	553	19.3
Missouri	954	18.5	996	18.2	1,164	20.6
Montana	137	17.0	130	17.5	147	21.3
Nebraska	294	18.2	290	18.8	317	22.0
Nevada	165	14.9	205	14.6	289	17.8
New Hampshire	172	15.5	204	14.5	281	17.0
New Jersey	1,418	18.3	1,509	18.0	1,770	20.0
New Mexico	220	14.4	255	14.7	329	17.1
New York	3,225	18.0	3,226	18.0	3,615	19.9
North Carolina	1,092	16.6	1,316	17.1	1,711	19.6
North Dakota	117	17.8	107	18.0	114	21.5
Ohio	1,906	17.5	1,915	17.5	2,124	19.7
Oklahoma	556	17.2	552	18.9	625	23.5
Oregon	495	17.6	485	16.7	605	20.7
Pennsylvania	2,450	20.3	2,364	19.6	2,561	21.3
Rhode Island	198	19.8	194	18.5	219	19.9
South Carolina	532	15.1	624	15.7	811	18.8
South Dakota	134	18.7	130	18.2	142	20.2
Tennessee	837	17.0	941	17.4	1,174	20.5
Texas	2,324	13.7	2,664	14.9	3,377	18.8
Utah	192	11.2	208	11.3	261	13.9
Vermont	90	15.8	95	15.3	115	17.5
Virginia	912	15.0	1,084	14.9	1,424	17.3
Washington	737	15.5	796	15.3	1,052	19.6
West Virginia	356	19.2	323	19.6	339	22.9
Wisconsin	860	17.7	857	17.7	964	20.7
Wyoming	57	12.0	52	12.7	60	16.4

SOURCE OF DATA: U.S. Bureau of the Census, Current Population Reports, Series P-25 (Administration in Aging).

TABLE 2c

PERSONS 60+ YEARS OLD BY SELECTED AGE GROUPS FOR STATES (1989)

Age Group: State:	Number (thousands)				Selected ages as % of 60+		
	60+	65+	75+	85+	65+	75+	85+
U.S., total	41,851	30,984	12,802	3,042	74.0	30.6	7.3
Alabama	697	523	216	48	75.0	31.0	6.9
Alaska	35	22	6	1	62.0	18.3	3.7
Arizona	624	464	180	36	74.5	28.8	5.8
Arkansas	462	356	153	35	76.9	33.1	7.6
California	4,245	3,071	1,234	293	72.4	29.1	6.9
Colorado	438	324	131	32	74.1	29.9	7.4
Connecticut	600	441	184	45	73.5	30.7	7.5
Delaware	112	79	30	7	71.2	27.0	6.6
District of Columbia	103	76	30	8	73.5	29.5	7.4
Florida	3,027	2,277	944	202	75.2	31.2	6.7
Georgia	900	653	260	58	72.5	28.9	6.4
Hawaii	171	119	44	10	69.7	25.9	6.0
Idaho	154	121	50	11	78.6	32.7	7.2
Illinois	1,954	1,437	602	147	73.6	30.8	7.5
Indiana	936	694	289	71	74.1	30.8	7.6
Iowa	553	428	198	55	77.5	35.7	9.9
Kansas	452	343	157	42	76.0	34.8	9.3
Kentucky	627	472	198	47	75.2	31.5	7.5
Louisiana	649	487	194	46	75.1	30.0	7.0
Maine	219	164	71	18	74.9	32.4	8.2
Maryland	715	509	195	46	71.1	27.2	6.4
Massachusetts	1,093	813	350	90	74.4	32.0	8.2
Michigan	1,501	1,100	441	105	73.3	29.4	7.0
Minnesota	725	549	248	68	75.7	34.3	9.4
Mississippi	430	326	139	33	75.9	32.4	7.6
Missouri	954	719	320	79	75.4	33.5	8.3
Montana	137	106	44	11	77.4	32.4	7.8
Nebraska	294	224	106	29	76.4	36.0	9.9
Nevada	165	121	39	7	73.4	23.5	4.3
New Hampshire	172	126	53	13	73.4	31.0	7.7
New Jersey	1,418	1,021	412	95	72.0	29.0	6.7
New Mexico	220	161	43	14	73.1	28.9	6.4
New York	3,225	2,341	992	245	72.6	30.8	7.6
North Carolina	1,092	798	312	70	73.1	28.5	6.4
North Dakota	117	92	43	11	78.2	36.8	9.2
Ohio	1,906	1,399	566	136	73.4	29.7	7.2
Oklahoma	556	428	189	45	77.1	34.0	8.2
Oregon	495	392	164	39	79.2	33.1	7.9
Pennsylvania	2,450	1,819	740	169	74.3	30.2	6.9
Rhode Island	198	148	63	15	74.6	31.8	7.7
South Carolina	532	390	145	31	73.4	27.2	5.9
South Dakota	134	103	47	13	76.8	35.2	9.8
Tennessee	837	625	259	59	74.6	30.9	7.1
Texas	2,324	1,714	707	165	73.7	30.4	7.1
Utah	192	146	59	13	76.4	31.0	6.7
Vermont	90	68	30	8	75.4	33.0	8.6
Virginia	912	657	255	60	72.1	28.0	6.6
Washington	737	567	231	55	77.0	31.3	7.5
West Virginia	356	272	113	26	76.3	31.7	7.3
Wisconsin	860	652	288	73	75.7	33.4	8.5
Wyoming	57	46	19	5	81.6	33.3	7.9

SOURCE OF DATA: U.S Bureau of the Census, Current Population Reports, Series P-25 (Administration on Aging).

Table 3

ESTIMATED OLDER POPULATION OF PERSONS WITH DEVELOPMENTAL DISABILITIES BY STATE

State	1990 Population*	Persons 55+*	Persons 60+*	Persons with DD 55+	Persons with DD 60+
U.S., total	248,239	52,577	41,857	208,730	166,140
Alabama	4,118	875	697	3,465	2,760
Alaska	527	52	35	206	139
Arizona	3,556	770	624	3,049	2,471
Arkansas	2,406	566	462	2,241	1,829
California	29,063	5,438	4,245	21,534	16,810
Colorado	3,317	561	438	2,221	1,734
Connecticut	3,239	755	600	2,989	2,376
Delaware	673	144	112	570	443
District of Columbia	604	129	103	510	407
Florida	12,671	3,661	3,027	14,497	11,986
Georgia	6,436	1,168	900	4,625	3,564
Hawaii	1,112	219	171	867	677
Idaho	1,014	188	154	744	609
Illinois	11,658	2,467	1,954	9,769	7,737
Indiana	5,593	1,178	936	4,664	3,706
Iowa	2,840	674	553	2,669	2,189
Kansas	2,513	559	452	2,213	1,789
Kentucky	372	685	623	2,712	2,467
Louisiana	4,382	814	649	3,223	2,570
Maine	1,222	273	219	1,081	867
Maryland	4,694	925	715	3,663	2,831
Massachusetts	5,913	1,359	1,093	5,382	4,328
Michigan	9,273	1,895	1,501	7,504	5,944
Minnesota	4,353	902	725	3,572	2,871
Mississippi	2,621	535	430	2,119	1,703
Missouri	5,159	1,187	954	4,701	3,778
Montana	806	169	137	669	543
Nebraska	1,611	368	294	1,457	1,164
Nevada	1,111	213	165	843	653
New Hampshire	1,107	218	172	863	681
New Mexico	1,528	281	220	1,113	871
New Jersey	7,736	1,802	1,418	7,135	5,615
New York	17,950	4,094	2,225	16,212	8,811
North Carolina	6,571	1,387	1,092	5,493	4,324
North Dakota	660	143	117	566	463
Ohio	10,907	2,399	1,906	9,500	7,548
Oklahoma	3,224	688	556	2,724	2,202
Oregon	2,820	597	495	2,364	1,960
Pennsylvania	12,040	3,025	2,450	11,979	9,702
Rhode Island	998	242	198	958	784
South Carolina	3,512	677	532	2,681	2,107
South Dakota	715	165	134	653	531
Tennessee	4,940	1,056	837	4,182	3,315
Texas	16,991	2,971	2,324	11,765	9,203
Utah	1,707	240	192	950	760
Vermont	567	112	90	444	356
Virginia	6,098	1,176	932	4,657	3,691
Washington	4,761	912	737	3,612	2,919
West Virginia	1,857	435	356	1,723	1,410
Wisconsin	4,867	1,066	860	4,221	3,406
Wyoming	475	69	57	273	226

Based upon as estimate of 3.96 older persons with a developmental disability per 1000 older persons in the general population (see pp 24-26).
* numbers in thousands

AGREEMENT BETWEEN U.S. ADMINISTRATION ON AGING AND U.S. ADMINISTRATION ON DEVELOPMENTAL DISABILITIES

Introduction

The Administration on Aging (AoA) was created under the Older Americans Act of 1965 and is the only Federal agency devoted exclusively to the concerns and potential of America's older population. AoA services as the visible advocate on behalf of the elderly within the Department of Health and Human Services and other Federal agencies and national organizations administering programs affecting older people. The major goal of the Administration on Aging is to help older people live more meaningful, independent, and dignified lives in their own homes and communities for as long as possible.

The Administration on Developmental Disabilities (ADD) is the lead agency within the Department of Health and Human Services responsible for planning and carrying out programs which promote the self-sufficiency and protect the rights of the nearly four million Americans with developmental disabilities. The major goal of the Administration on Developmental Disabilities is to work in partnership with State governments, local communities and the private sector to increase the social and economic integration of individuals with developmental disabilities into the fabric of society.

The purpose of this agreement is to improve the coordination of programs administered by the Administration on Aging and the Administration on Developmental Disabilities which relate to the welfare of older persons with developmental disabilities.

Background

It is estimated that four out of every 1,000 older adults have a developmental disability. The total number of elderly persons in the United States who are developmentally disabled is estimated to be as high as one-half million persons. These older persons are in double jeopardy. Their problems are complicated by long-standing physical or mental impairments and they frequently need individualized housing, day-care, and other supportive services. Assistance, through the provision of appropriate services, to this priority older population can be made available and accessible within the community through a comprehensive, coordinated, community-based service system. This system of services should be designed to enable older persons with developmental disabilities to attain and maintain emotional well being and independent living.

The Older Americans Act now contains many requirements for services to elderly disabled people and cooperation with agencies and organizations regarding the developmentally disabled. For example, the Act requires the State Agency on Aging to establish and operate an Office of the State Long Term Care Ombudsman. This Office is required to coordinate ombudsman services with the protection and advocacy systems for individuals with developmental disabilities and mental illness established under Part A of the Developmental Disabilities Assistance and Bill of Rights Act and under the Protection and Advocacy for Mentally Ill Individuals Act of 1986.

With respect to the needs of elderly persons with severe disabilities, the Act requires State plan assurances for the coordination of planning, identification, assessment of needs, and services with State agencies primarily responsible for disabled, including severely disabled, persons. The State plan must also contain an assurance that the State will work with these agencies to develop collaborative programs to meet the needs of older individuals with disabilities.

There is a need for the Administration on Aging and the Administration on Developmental Disabilities to undertake the development of collaborative activities to improve the coordination of programs administered by the Administration on Aging and the Administration on Developmental Disabilities which promote the independence and well-being of older persons with developmental disabilities.

Scope of the Agreement

The immediate objective of this agreement is for the Administration on Aging and the Administration on Developmental Disabilities to discuss, and develop action plans for, joint initiatives which improve the coordination of the Administration on Aging and the Administration on Developmental Disabilities programs and activities in order to improve services to older persons with developmental disabilities, promote the integration of these individuals into the mainstream of society, and promote a better understanding of programs serving elderly and disabled persons between the National Network on Aging and the Developmental Disabilities Network.

Under this agreement, the Administration on Aging and the Administration on Developmental Disabilities agree to jointly develop and implement initiatives in support of the goals and objectives outlined below and to undertake the development of other collaborative activities which promote the independence and well-being of older persons with developmental disabilities.

Goal I

Promote a better understanding of programs serving elderly and disabled persons between the National Network on Aging and the Developmental Disabilities Network.

Objectives

1.To increase best practice and other information sharing/exchange between the Network on Aging and Developmental Disabilities Network.

2.To stimulate linkages between the Ombudsman and Protection and Advocacy Programs.

3.To explore potential linkages between the Aging Resource Centers and University Affiliated Programs.

4.To encourage the development of memoranda of understanding between the State Developmental Disabilities Councils and State Agencies on Aging.

Goal II

To demonstrate a commitment at the national level between the Administration on Aging and the Administration for Developmental Disabilities regarding serving older persons with developmental disabilities.

Objectives

1.1 To provide policy guidance at the national level between the Administration on Aging and the

Administration for Developmental Disabilities regarding serving older persons with developmental disabilities.

2.To promote training of Network on Aging and Developmental Disabilities staff and others regarding the abilities and unmet needs of older persons who are developmentally disabled.

3.To increase collaboration and linkages between national organizations and Federal, State, and local agencies serving the older persons who are developmentally disabled.

4.To jointly develop a priority area on elderly persons with developmental disabilities for the discretionary funds announcements.

Goal III

Improve services to older persons with developmental disabilities.

Objectives

l.To identify the unmet needs of older persons with developmental disabilities.

2.To facilitate the provision of quality services in intermediate care facilities which meet the needs of older persons who are mentally retarded.

3.To promote training of health care professionals to provide services to older persons with developmental disabilities.

4.To promote training of family caregivers on how to care for older persons with developmental disabilities.

5.To promote the successful integration of older persons with developmental disabilities in aging network programs (mainstreaming those elderly persons who are developmentally disabled as participants and volunteers at senior centers and nutrition sites).

Administration of Memorandum of Understanding

The Administration on Aging and Administration on Developmental Disabilities jointly agree to:

l.Designate staff to be responsible for administering all aspects of this agreement; and

2.Designate staff of Administration on Aging and the Administration on Developmental Disabilities to meet regularly to review the progress of the joint agreement and to identify new joint initiatives.

Period of Agreement

This agreement is effective upon signature and shall continue in effect until terminated by either party.

Authority

The Economy Act of 1932, as amended (311].S.C. 1535)

Modification or Cancellation Provision

This agreement may be modified or amended by written agreement of both parties. Requires for modification and amendments to the agreement may be initiated by either party through written notification to either party.

Costs

To be determined upon the completion of specific action plans for dissemination activities and/or research and demonstration projects.

Acceptance and Signature of Each Approving Party

Joyce T. Berry, Ph.D.
Acting Commissioner on Aging
Administration on Aging
U. S. Department of Health and Human Services

September 27, 1989

Will Wolstein
Acting Commissioner
Administration on Developmental Disabilities
U. S. Department of Health and Human Services

September 27, 1989

SAMPLE AGREEMENT BETWEEN STATE UNIT ON AGING AND STATE DEVELOPMENTAL DISABILITIES AGENCY

Memorandum of Understanding
Relative to Older New Yorkers With a Developmental Disability
Between the New York State Office for the Aging
and
The New York State Office of Mental Retardation
and Developmental Disabilities

This agreement is entered into by and between the New York State Office for the Aging (SOFA) acting by and through the Director with Offices at Two Empire State Plaza, Albany, NY 12223, and the New York State Office of Mental Retardation and Developmental Disabilities (OMRDD) acting by and through the Commissioner with offices at 44 Holland Avenue, Albany, NY 12229.

Whereas OMRDD is the state agency responsible for providing residential and community services for persons with a developmental disability in New York State, and

Whereas SOFA is the state agency responsible for implementing and stimulating programs and policies both through the aging network and other state agencies on behalf of all older New Yorkers, and

Whereas aging network means agencies which receive monies administered by the SOFA, and

Whereas the State and recent federal Older Americans Act amendments recognize the increasing number of older persons with a developmental disability, and

Whereas older New Yorkers with a developmental disability are eligible for aging network services, and

Whereas both agencies agree that the integration of capable older New Yorkers with a developmental disability within aging network programs is feasible and warranted, and

Whereas SOFA and OMRDD believe a coordinated multi-agency approach can more effectively meet the needs of older New Yorkers with a developmental disability, SOFA and OMRDD agree:

- to establish and maintain an interagency services coordination committee to address issues of common concern, coordinate planning and services, and resolve problems;
- to encourage local coordination of planning, needs identification, and development of services between local Offices for the Aging and OMRDD district offices and/or constituent provider agencies;
- to establish mechanisms for coordinating funding of services to older New Yorkers with a developmental disability including ensuring coverage of the additional costs stemming from provision of services such as supplemental staff assistance, transportation, or other activities within aging network services;
- to assist local Offices for the Aging and OMRDD district offices or its constituent agencies to develop arrangements for reimbursement of additional of aging network services;
- to establish mechanisms to cover services reporting and case record sharing requirements;
- to assist each other by sharing technical information, training resources, and providing cross-training to agencies providing services to older New Yorkers with a developmental disability within both networks; to cooperate on common projects involving grant or other external funding that would benefit older New Yorkers with a developmental disability; and
- to encourage New York's colleges and universities to address the issues of aging among New York's older population of persons with a developmental disability.

Therefore, SOFA and OMRDD agree to the following:

Office for the Aging agrees, only to the extent resources are available, to:

- request the State's local Offices for the Aging to enter into a planning process with the relevant OMRDD district office on specific service projects, and such planning processes would include not only the local developmental disability and aging offices, but also older adults from the planning and service areas;
- share technical resources, such as videos, films and publications, free of charge, with OMRDD and its district offices;
- provide technical assistance in relevant areas to OMRDD, its district offices and constituent agencies;
- engage in advocacy activities on behalf of older New Yorkers with a developmental disability;
- facilitate the assimilation of disability agency senior programs into the local aging network;
- enter into cooperative endeavors that would benefit older New Yorkers with a developmental disability and their families; and
- request the state's colleges and university-based centers of aging or geriatric education centers to develop intramural and extramural activities related to aging and developmental disabilities.

OMRDD agrees, only to the extent resources are available, to:

- request OMRDD district offices to enter into a planning process with the state's local Offices for the Aging on specific service projects;
- share technical resources, such as videos, films, and publications, free of charge, with SOFA and the state's local Offices for the Aging;
- provide technical assistance in relevant areas to

OFA and the state's local Offices for the Aging;

- engage in advocacy activities on behalf of older New Yorkers with a developmental disability;
- enter into cooperative endeavors that would benefit older New Yorkers with a developmental disability and their families;
- share information on available funding support to aging network programs specifically or individually serving older New Yorkers with a developmental disability;
- agree to assume the additional costs of providing services within aging network programs for older New Yorkers with a developmental disability;
- assume the responsibility of recordkeeping and reporting requirements, set by OMRDD, for older New Yorkers in aging network programs and services for whom such requirements apply; and
- to cooperate in cross-training endeavors directed toward local programs.

This memorandum of understanding is effective on the 31st day of January, 1990 and shall be in effect until terminated by mutual agreement

Jane Gould
Director, State Office for the Aging
Retardation & Developmental Disabilities

Elin M. Howe
Commissioner, State Office of Mental

SAMPLE AGREEMENT BETWEEN AREA AGENCY ON AGING AND LOCAL OFFICE OF STATE DEVELOPMENTAL DISABILITIES AGENCY

Memorandum of Understanding
Relative to Older New Yorkers With a Developmental Disability
Between the Oneida County Office for Aging
and
The Rome Developmental Disabilities Services Office

This agreement is entered into by the Oneida County Office for the Aging, acting by and through the Director, with offices at 800 Park Avenue, Oneida County Office Building, Ninth Floor, Utica, New York 13501 and the Rome Developmental Disabilities Services Office, through the Director, with offices at the Administrative Complex, Rome DDSO, Box 550, Rome, New York 13440.

- **Whereas** the Rome DDSO is the district agency of OMRDD, responsible for providing residential and community services for persons with a developmental disability in Oneida County, and
- **Whereas** the Oneida County OFA is the duly designated area agency on aging, responsible for implementing and stimulating programs and policies, both through the aging network and other state and county agencies, on behalf of all older residents in Oneida County, and
- **Whereas** aging network means agencies which receive monies administered by the State Office for the Aging, and
- **Whereas** the State, Oneida County, and recent federal Older Americans Act amendments recognize the increasing number of older persons with a developmental disability, and
- **Whereas** older New Yorkers in Oneida County with a developmental disability are eligible for aging network services and
- **Whereas** both agencies agree that the integration of capable older New Yorkers in Oneida County with a developmental disability within aging network programs is feasible and warranted, and
- **Whereas** the Oneida County OFA and the Rome DDSO believe a coordinated multi-agency approach can more effectively meet the needs of older New Yorkers in Oneida County with a developmental disability, the Oneida County Office for the Aging and the Rome DDSO agree:

- to identify the Oneida County Aging and MRDD Coalition as the formal inter-agency services coordination committee to address issues of common concern, coordinate planning and services to maximize program opportunities as well as to resolve problems;
- to establish an Advisory Council, consisting of the Rome DDSO Elderly Advisory Committee and representatives from the Oneida County OFA, who meet at least two times a year to review progress on the MOU and revise when appropriate;
- to encourage continued local coordination of planning, needs identification, and development of services between the County OFA and the Rome DDSO and/or constituent provider agencies, through the Oneida County Aging and MRDD Coalition;
- to encourage reciprocity of services from both agencies in planning, coordination, and delivery of integrative programs;
- to establish mechanisms for sharing of information on funding sources for older persons with a developmental disability as well as developing mechanisms for coordinating funding of services such as supplemental staff assistance, transportation sharing, or other activities and resources as appropriate;
- to establish mechanisms to cover services reporting and case record sharing requirements;
- to establish a protocol and mechanism for joint confidential case presentations, as appropriate;
- to assist each other by sharing technical information, training resources, and providing cross-training to agencies providing services to older persons with a developmental disability within both networks;
- to cooperate on common projects involving grant or other external funding that would benefit older persons.
- to encourage Oneida County's colleges, universities and educational systems such as BOCES and local public schools, to address the issues of individuals who are aging and MRDD, through curriculum infusion;
- to establish mechanisms for cross advocacy by the two agencies or its constituent provider agencies.

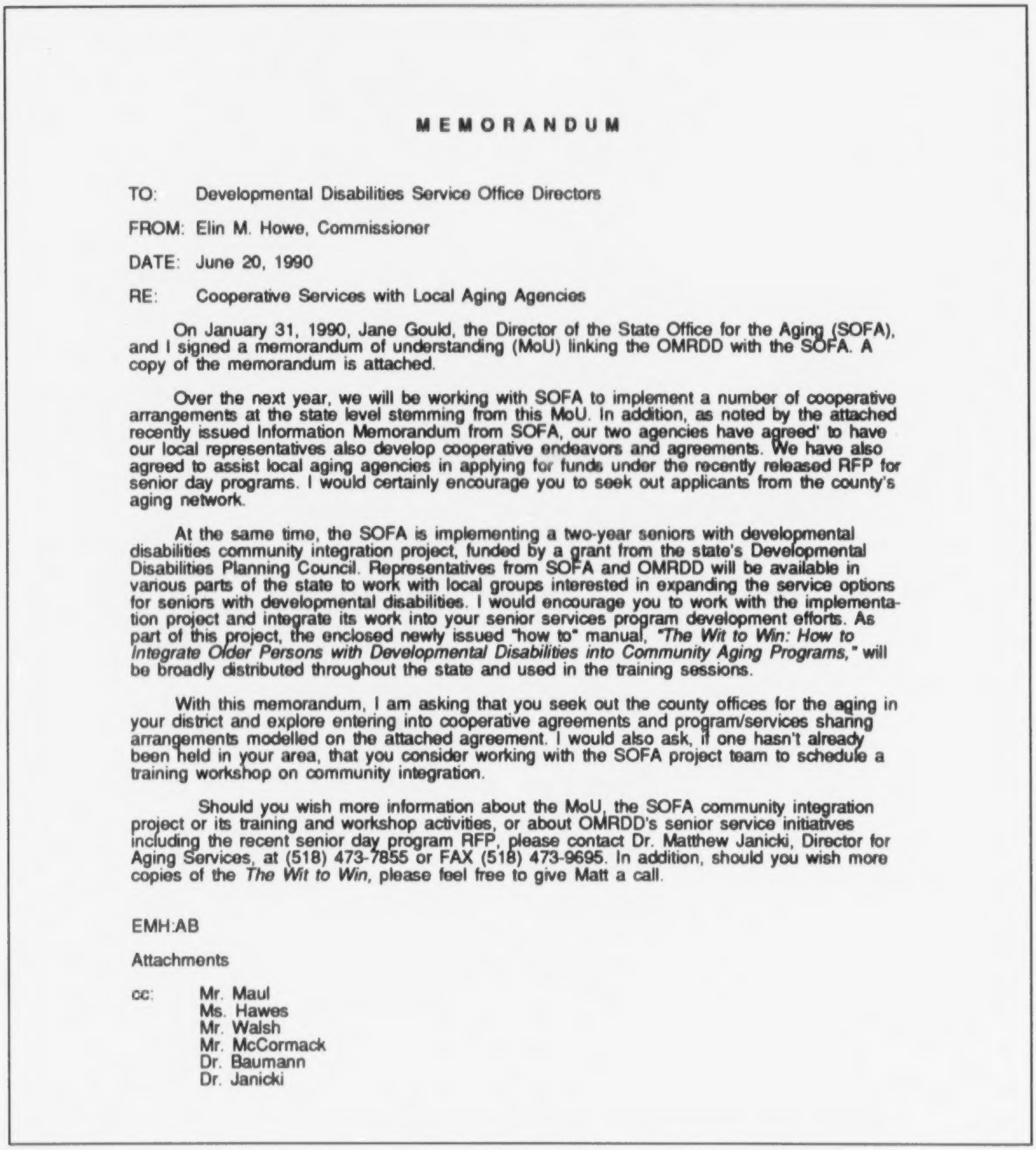
Therefore, the Oneida County Office for the Aging agrees, and the Rome DDSO agrees, only to the extent resources are available to this Memorandum of Understanding.

This Memorandum of Understanding is effective on October 9, 1990 and shall be in effect until terminated by mutual agreement of the local agencies in concert with the Memorandum of Understanding Relative to Older New Yorkers With a Developmental Disability, Between the New York State Office for The Aging and the New York State Office of Mental Retardation and Developmental Disabilities, signed into effect on the 31st day of January 1990.

Philip Catchpole
Director
Rome Developmental
Disabilities Services Office

Theresa Laper
Director
Oneida County Office
for the Aging

SAMPLE FIELD ANNOUNCEMENT REGARDING STATE LEVEL AGREEMENT



MEMORANDUM

TO: Developmental Disabilities Service Office Directors

FROM: Elin M. Howe, Commissioner

DATE: June 20, 1990

RE: Cooperative Services with Local Aging Agencies

On January 31, 1990, Jane Gould, the Director of the State Office for the Aging (SOFA), and I signed a memorandum of understanding (MoU) linking the OMRDD with the SOFA. A copy of the memorandum is attached.

Over the next year, we will be working with SOFA to implement a number of cooperative arrangements at the state level stemming from this MoU. In addition, as noted by the attached recently issued Information Memorandum from SOFA, our two agencies have agreed' to have our local representatives also develop cooperative endeavors and agreements. We have also agreed to assist local aging agencies in applying for funds under the recently released RFP for senior day programs. I would certainly encourage you to seek out applicants from the county's aging network.

At the same time, the SOFA is implementing a two-year seniors with developmental disabilities community integration project, funded by a grant from the state's Developmental Disabilities Planning Council. Representatives from SOFA and OMRDD will be available in various parts of the state to work with local groups interested in expanding the service options for seniors with developmental disabilities. I would encourage you to work with the implementation project and integrate its work into your senior services program development efforts. As part of this project, the enclosed newly issued "how to" manual, *"The Wit to Win: How to Integrate Older Persons with Developmental Disabilities into Community Aging Programs,"* will be broadly distributed throughout the state and used in the training sessions.

With this memorandum, I am asking that you seek out the county offices for the aging in your district and explore entering into cooperative agreements and program/services sharing arrangements modelled on the attached agreement. I would also ask, if one hasn't already been held in your area, that you consider working with the SOFA project team to schedule a training workshop on community integration.

Should you wish more information about the MoU, the SOFA community integration project or its training and workshop activities, or about OMRDD's senior service initiatives including the recent senior day program RFP, please contact Dr. Matthew Janicki, Director for Aging Services, at (518) 473-7855 or FAX (518) 473-9695. In addition, should you wish more copies of the *The Wit to Win,* please feel free to give Matt a call.

EMH:AB

Attachments

cc: Mr. Maul
Ms. Hawes
Mr. Walsh
Mr. McCormack
Dr. Baumann
Dr. Janicki

OFFICE OF MENTAL RETARDATION AND DEVELOPMENTAL DISABILITIES

REQUEST FOR PROPOSALS

SENIOR DAY PROGRAMS

This is to announce the anticipated availability of funding to provide **senior day programs for older and elderly individuals with mental retardation/developmental disabilities.**

> *Please be aware that successful proposals for senior day programs funded previously by OMRDD had an average per diem of $21.45, were exempt from current OMRDD certification requirements, made use of volunteers -- particularly Senior Companions, admitted both seniors with developmental disabilities and seniors similarly functionally impaired with latelife disabilities, had some relationship to the community's other generic senior programs or services, and generally functioned as demonstrations of novel program models. In the future, senior day programs funded under this initiative may be requested to operate under the State Office for the Aging's social model adult day care standards.*
>
> *Applicants are advised that per diem rates may not exceed $25/day, including transportation (unless other sources of funds are to be used), and that the expected start-up date for the approved projects is October 1, 1990. OMRDD welcomes proposals for full and part-time programs from agencies within both the developmental disabilities provider system and the aging network.*

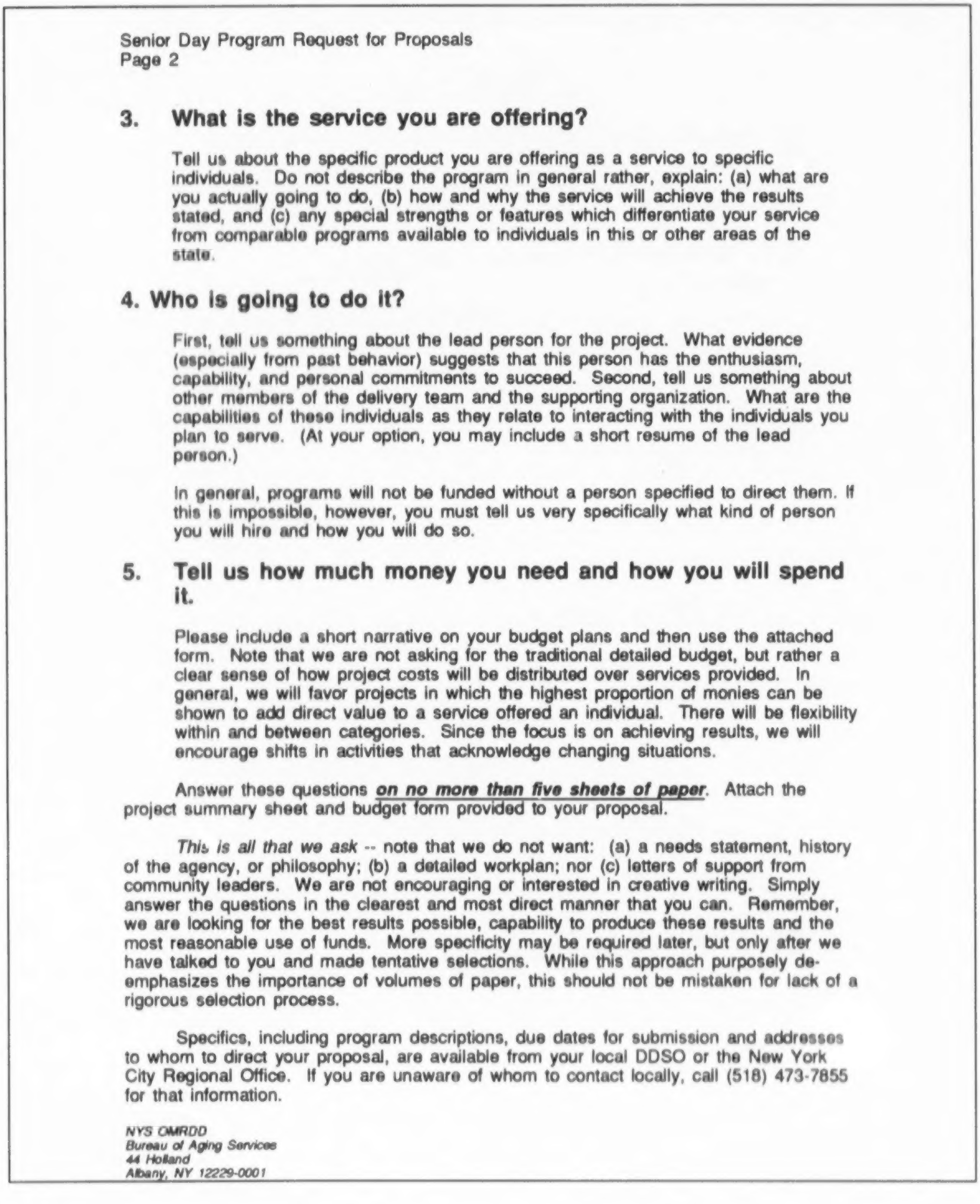
In preparing your proposal, we are asking only for that information directly relevant to forecasting the likelihood that the proposed project will achieve its intended results. The practice of having selection decisions made at the local level will continue as in the past. In preparing your application, please note that we are looking for a short project summary (less than 200 words) as per the attached sheet and answers to the following questions for each program area you wish to apply for.

1. Who will you serve?

Please identify the need and specify the characteristics of the people you will serve as well as the needs which you will address. Be as specific as possible in describing who you will and will not include, and why. Include the number of individuals you expect to serve, the capacity of your proposed program, and how you determined that a need exists in your area and will continue to exist beyond the initial number of persons you plan to serve.

2. What results are you committed to achieving?

Please state the outcomes of the proposed project specifically and in terms of the individuals you will help. Be as specific as possible and address results or the impact of your proposed service, not activities to be completed. For example, you may wish to place 15 seniors into an adult day care program, (result), but in order to do so, will need to do outreach to over 200 families or organizations (activity to achieve result). As you specify who will be helped and in what ways, please note that both the quantity and quality of results are important.



Senior Day Program Request for Proposals
Page 2

3. What is the service you are offering?

Tell us about the specific product you are offering as a service to specific individuals. Do not describe the program in general rather, explain: (a) what are you actually going to do, (b) how and why the service will achieve the results stated, and (c) any special strengths or features which differentiate your service from comparable programs available to individuals in this or other areas of the state.

4. Who is going to do it?

First, tell us something about the lead person for the project. What evidence (especially from past behavior) suggests that this person has the enthusiasm, capability, and personal commitments to succeed. Second, tell us something about other members of the delivery team and the supporting organization. What are the capabilities of these individuals as they relate to interacting with the individuals you plan to serve. (At your option, you may include a short resume of the lead person.)

In general, programs will not be funded without a person specified to direct them. If this is impossible, however, you must tell us very specifically what kind of person you will hire and how you will do so.

5. Tell us how much money you need and how you will spend it.

Please include a short narrative on your budget plans and then use the attached form. Note that we are not asking for the traditional detailed budget, but rather a clear sense of how project costs will be distributed over services provided. In general, we will favor projects in which the highest proportion of monies can be shown to add direct value to a service offered an individual. There will be flexibility within and between categories. Since the focus is on achieving results, we will encourage shifts in activities that acknowledge changing situations.

Answer these questions ***on no more than five sheets of paper***. Attach the project summary sheet and budget form provided to your proposal.

This is all that we ask -- note that we do not want: (a) a needs statement, history of the agency, or philosophy; (b) a detailed workplan; nor (c) letters of support from community leaders. We are not encouraging or interested in creative writing. Simply answer the questions in the clearest and most direct manner that you can. Remember, we are looking for the best results possible, capability to produce these results and the most reasonable use of funds. More specificity may be required later, but only after we have talked to you and made tentative selections. While this approach purposely de-emphasizes the importance of volumes of paper, this should not be mistaken for lack of a rigorous selection process.

Specifics, including program descriptions, due dates for submission and addresses to whom to direct your proposal, are available from your local DDSO or the New York City Regional Office. If you are unaware of whom to contact locally, call (518) 473-7855 for that information.

NYS OMRDD
Bureau of Aging Services
44 Holland
Albany, NY 12229-0001

Administration on Developmental Disabilities
HHH Building
200 Independence Avenue, SW
Washington, DC 20201
202/245-2890

Administration on Aging
US Department of Health & Human Services
330 Independence Avenue, S.W.
Washington, DC 20201
202/619-0011

American Association of Homes for the Aging
1129 20th Street, N.W.
Suite 400
Washington, D.C. 20036
202/296-5960

American Association of University Affiliated
Programs
8630 Fenton Street
Suite 410
Silver Spring, MD 20910
301/588-8252

American Association on Mental Retardation
1719 Kalorama Road, N.W.
Washington, DC 20009
202/387-1968

Association for Retarded Citizens-US
500 East Border Street
Arlington, TX 76010
817/261-6003

Association for Gerontology in
Higher Education
1001 Connecticut Avenue, N.W.
Suite 410
Washington, D.C. 20036-5504
202/429-9277

Gerontological Society of America
1411 K Street, N.W.
Suite 300
Washington, DC 20005
202/842-1275

National Association of State
Mental Health Program Directors, Inc.
1101 King Street
Suite 160
Alexandria, VA 22314
703/739-9333

National Association of Protection
& Advocacy Systems
300 "Eye" Street NE
Suite 202
Washington, DC 20002
202/546-8202

National Association of Private
Residential Facilities
4200 Evergreen Lane, Suite 315
Annandale, VA 22003
703/642-6614

National Association of Area Agencies
on Aging
1112 16th Street, N.W.
Suite 100
Washington, DC 20036
202/296-8130

National Association of State Mental
Retardation Program Directors, Inc.
113 Oronoco Street
Alexandria, VA 22314
703/683-4202

National Association of Developmental
Disabilities Councils
1234 Massachusetts Avenue, N.W.
Suite 103
Washington, DC 20005
202/347-1234

National Association of State Units on Aging
2033 K Street NW
Suite 304
Washington, DC 20006
202/785-0707

National Council on the Aging
409 Third Street, S.W.
Washington, D.C. 20024
202/479-1200

National Institute on Aging
Building 31, Room 5C 35
Bethesda, MD 20892
202/496-9265

United Cerebral Palsy Associations, Inc.
Suite 1112
1522 "K" Street, N.W.
Washington, D.C. 20005
202/842-1266

World Institute on Disability
510 16th Street
Oakland, CA 94612
415/763-4100

Section 1

State developmental disabilities/aging plans and planning for an older developmentally disabled population (Janicki, M.P., Ackerman, L. & Jacobson, J.W.; *Mental Retardation*, 1986, *23*, 297-301).

Aging... A Shared Experience: Discussion Guide (available from NYS OMRDD, 44 Holland Avenue, Albany, NY 12229-0001).

On the Feasibility of Different Pension Support Systems for New York State Residents with a Developmental Disability (available from the New York State Developmental Disabilities Planning Council, 155 Washington Avenue, Albany, NY 12210).

Standards for Social Adult Day Care (available from the New York State Office for the Aging, Two Empire State Plaza, Albany, NY 12223-0001).

New Directions for Seniors: Senior Day Program Demonstrations (available from NYS OMRDD, 44 Holland Avenue, Albany, NY 12229).

Whitehaven: Personal Care Vender Unit and Community Residence for Seniors (available from NYS OMRDD, 44 Holland Avenue, Albany, NY 12229).

Sharing Activities: A Report on an Integration Project between the Oneida County ARC and the Cornhill Senior Center (available from NYS OMRDD, 44 Holland Avenue, Albany, NY 12229).

When Persons with Developmental Disabilities Age (videocassette available from the New York State Developmental Disabilities Planning Council, 155 Washington Avenue, Albany, NY 12210).

Section 2

Contemporary Issues in the Aging of Persons with Mental Retardation and other Developmental Disabilities (M.P. Janicki, M.M. Seltzer, & M.W. Krauss; a Rehabilitation Research Review available from the National Rehabilitation Information Center, 8455 Colesville Road, Suite 935, Silver Spring, MD 20910).

Aging and Mental Retardation: Extending the Continuum (M.M. Seltzer and M.W. Krauss; available from the American Association on Mental Retardation, 1719 Kalorama Road, N.W., Washington, DC 20009).

Glossary of Important Terms, Concepts, and Resources in the Fields of Aging and Developmental Disabilities (available from the Hunter-Brookdale Center on Aging, 425 East 25th Street, New York, NY 10010).

"Demography and characteristics of aging and aged mentally retarded people" (in M. Janicki and H.M. Wisniewski, eds., *Aging and Developmental Disabilities: Issues and Approaches*, Paul H. Brookes Publishing Company, Baltimore, MD, 1985).

Section 3

An Orientation Manual to the Older Americans Act (Susan Coombs Ficke; available from the National Association of State Units on Aging, 2033 K Street, N.W., Washington, DC 20005).

Section 6

Standards and Guidelines for Adult Day Care (available from the National Council on the Aging, 409 Third Street, S.W., Washington, DC 20024).

The Second Fifty Years: Promoting Health and Preventing Disability (available from National Academy Press, 2101 Constitution Avenue, N.W., Washington, DC 20418).

Parents of the Adult Developmentally Disabled (Meg Gold; available from the Hunter-Brookdale Center on Aging, 425 East 25th Street, New York, New York 10010-2590).

Aging and Developmental Disabilities: Challenges for the 1990s (proceedings of the Boston Roundtable on Research Issues and Applications in Aging and Developmental Disabilities; available from Special Interest Group in Aging, American Association on Mental Retardation, 1719 Kalorama Road, N.W., Washington, DC 20009).

Guardianship of Adults (Resource Manual and Participant's Guide) (available from the Oklahoma Department of Human Services (Sequoyah Memorial Office Building, P.O. Box 25352, Oklahoma City, OK 73125).

Retirement Planning for Older Persons with Developmental Disabilities (available from the UMKC Institute for Human Development, 2220

Holmes Street, 3rd Floor, Kansas City, MO 64108-2676).

On the Feasibility of Different Pension Support Systems for New York State Residents with a Developmental Disability (available from the New York State Developmental Disabilities Planning Council, 155 Washington Avenue, Albany, NY 12210).

The Wit to Win: How to Integrate Older Persons with Developmental Disabilities into Community Aging Programs, (available from the New York State Office for the Aging, Agency Building Two, Empire State Plaza, Albany, New York 12223-0001).

Section 8

Personnel for Health Needs of the Elderly through the Year 2020 (available from the National Institute on Aging, Bethesda, Maryland 20892).

Section 9

Aging and Developmental Disabilities in Rural America (available from National Resource Center for Rural Elderly, University of Missouri-Kansas City, 5100 Rockhill Road, Scofield Hall, Kansas City, MO 64110-2499).

Aging in America: Implications for Vocational Rehabilitation and Independent Living (available from the University of Wisconsin-Stout, Research and Training Center, Stout Vocational Rehabilitation Institute, Menomonie, WI 54751).

Serving Seniors with Severe Disabilities (available from the Brookdale Center on Aging, Hunter College, 425 East 25th Street, New York, NY 10010-2590).

An Instructor's Guide to Training Volunteers: Companion Programs for Older Persons with Developmental Disabilities and their Non-Disabled Peers (available from the University of Missouri-Kansas City, Institute for Human Development, 2220 Holmes Street, Kansas City, MO 64108-2676).

Standards and Guidelines for Adult Day Care (available from the National Council on the Aging, 409 Third Street, S.W., Washington, DC 20024).

The National Adult Day Center Census - 89: A Descriptive Report (available from the Institute for Health & Aging, School of Nursing, University of California-San Francisco, San Francisco, CA 94143).

Senior Center Standards and Self-Assessment Workbook: Guidelines for Practice (available from the National Council on the Aging, 409 Third Street, S.W., Washington, DC 20024).

How to Start a Respite Service for People with Alzheimer's and Their Families: A Guide for Community-based Organizations (available from the Brookdale Center on Aging of Hunter College, 425 East 25th Street, New York, NY 10011).

Respite Guide: Running a Respite Care Program in the 1990's (available from the New York State Office for the Aging, Two Empire State Plaza, Albany, NY 12223).

Housing Options for Older Americans (available from the American Association of Retired Persons, Housing Program, 1909 K Street, N.W., Washington, DC 20049).

Housing Options Sourcebook for Older New Yorkers (available from New York State Office for the Aging, Two Empire State Plaza, Albany, NY 12223-0001).

Your Home: Your Choice: A Workbook for Older People and their Families (available from the American Association of Retired Persons, Housing Program, 1909 K Street, N.W., Washington, DC 20049.)

Home Equity Conversion (available from the New York State Office for the Aging, Agency Building Two, Empire State Plaza, Albany, NY 12223-0001).

The Do-able Renewable Home; Making Your Home Fit Your Needs (available from the American Association of Retired Persons, 1909 K Street, N.W., Washington, DC, 20049).